THE PERCEIVED EFFECTS OF MUSIC THERAPY
ON THE MENTAL AND PHYSICAL HEALTH
OF HOSPITALIZED ADOLESCENTS
WITH CYSTIC FIBROSIS

Master’s Thesis

Presented to

The Faculty of the Creative Arts in Therapy Program
College of Nursing and Health Professions
Drexel University

In Partial Fulfillment of the
Requirements of the Degree of Master of Arts

By

Caryn S. Widrick
Creative Arts in Therapy
August 2006
Dedication

As the thunder rolls
I barely hear You whisper through the rain
“T’m with you”
And as Your mercy falls
I raise my hands and praise the God who gives
And takes away

I’ll praise You in this storm
And I will lift my hands
For You are who You are
No matter where I am
Every tear I’ve cried
You hold in Your hand
You never left my side
And though my heart is torn
I will praise You in this storm

(Casting Crowns: “Praise You in This Storm”)

I would like to dedicate this work to the following people. Your enthusiasm and love of life in the face of adversity has been my inspiration and motivation to pursue this area of research. I am truly grateful.

To all the remarkable individuals and their loved ones who bravely battle cystic fibrosis every day with courage, strength and determination.

To the many whose battle has already been fought, including:

Jennifer M. Entler, my childhood classmate and friend with the bright smile, dynamic personality and kind heart, who first taught me about Cystic Fibrosis
Marvin Peter Jutzi
Kevin James Jutzi
Robin John Edwin Jutzi

You have touched my life.

To Aunt Grace and Uncle Merlin Jutzi for always lovingly sharing precious and touching memories of your sons with me. Your faith in God and dedication to family are indeed a blessing.
Acknowledgements

My deepest gratitude and appreciation to the following:

My advisor Paul Nolan, MCAT, MT-BC, LPC and other thesis committee members Flossie Ierardi, MM, MT-BC, LPC, and Barbara Jansma, MSN, CRNP, BC, who generously invested their time and expertise providing me with countless hours of assistance, advice and encouragement.

Patrick Lipawen, MA, MT-BC, who provided music therapy for the participants in this study, for the valuable gift of his time and enthusiastic participation.

The subjects who participated in this study and allowed me to interview them thus providing the data for this project.

The Children’s Hospital of Philadelphia for permitting me to conduct research at their facility.

My classmates from Hahnemann, a huge “wave” for their steadfast friendship and encouragement.

My mother, father, brother, grandmother and entire family for their unwavering love, support and most importantly their prayers.

I lift up my eyes up to the hills – where does my help come from?
My help comes from the Lord, the Maker of heaven and earth.
Psalm 121: 1, 2 NIV
Table of Contents

Dedication ..................................................................................................................... ii
Acknowledgements ...................................................................................................... iii
Table of Contents ......................................................................................................... iv
Abstract ....................................................................................................................... vi
CHAPTER 1: INTRODUCTION ................................................................................. 1
CHAPTER 2: LITERATURE REVIEW ...................................................................... 4
  Cystic Fibrosis .......................................................................................................... 4
    Genetics ...................................................................................................................... 4
    Diagnosis .................................................................................................................... 5
    Clinic .......................................................................................................................... 6
    Treatment .................................................................................................................... 7
Psychological Issues of Cystic Fibrosis .................................................................... 9
  Infancy and Pre-school .............................................................................................. 9
  School Age .................................................................................................................. 10
  Adolescence ................................................................................................................ 11
  Psychological Impact of Cystic Fibrosis ................................................................... 13
Psychological Effects of Hospitalization ................................................................ 15
Music Therapy ........................................................................................................... 16
  Music Therapy and Hospitalized Children ............................................................... 16
  Music Therapy and Cystic Fibrosis ........................................................................... 19
CHAPTER 3: METHODOLOGY .............................................................................. 21
  Design ......................................................................................................................... 21
  Description of Subjects ............................................................................................. 22
  Subject Selection Procedures .................................................................................... 22
  Subject Recruitment and Consent Procedures ........................................................... 23
  Clinical Procedures .................................................................................................... 23
  Protocol ......................................................................................................................... 24
  Data Collection ........................................................................................................... 24
  Data Analysis ............................................................................................................... 25
  Operational Definition of Variables ........................................................................... 28
CHAPTER 4: RESULTS ............................................................................................ 30
  Introduction .................................................................................................................. 30
  Background of Each Subject ...................................................................................... 30
    Table 1: Subject Information .................................................................................... 31
  Major Findings ............................................................................................................. 35
    Table 2: Subject Responses .................................................................................... 37
      Cognitive Responses ............................................................................................... 38
      Emotional Responses .............................................................................................. 43
      Physical Responses ................................................................................................. 46
      Interpersonal Experiences ....................................................................................... 48
CHAPTER 5: DISCUSSION ...................................................................................... 52
  Overview ...................................................................................................................... 52
  Description of Major Findings ................................................................................... 53
  Clinical Applications ................................................................................................. 58
Limitations of the Study............................................................ 60
Role of the Researcher............................................................. 62
Implications for Future Research............................................. 63
CHAPTER 6: SUMMARY AND CONCLUSIONS.......................... 67
REFERENCES........................................................................... 69
APPENDIX A............................................................................ 78
APPENDIX B............................................................................ 85
Cystic fibrosis (CF) is an inherited disease that mainly affects the digestive system and the lungs. An individual needs to manage his/her illness on a daily basis through various medications and therapeutic regimes. Hospitalization is often necessary for medical management or complications of the disease. Although the average lifespan of an individual with cystic fibrosis is 40 years of age, some still die as infants, children and young adults. There is no cure.

Music therapy may successfully enhance the well-being of hospitalized adolescents both emotionally and physically. The music therapist often addresses issues through fostering creativity, developing a supportive relationship, providing an outlet for expression and other participative methods.

The purpose of this study was to determine how young patients with cystic fibrosis perceived the effects of music therapy during their hospitalization. By way of personal interviews with six subjects the researcher has examined the outcome of music therapy as understood by the patients.

The most prevalent effects appeared to be in the cognitive and emotional response areas, with subjects reporting an improvement in coping skills, self-discovery, self-confidence, and a change in perspective, as well as decreased isolation and improved mood. Many subjects reported imagery experiences that provided for a change of mental focus to less stressful perspectives. A variety of physical benefits were reported by all of the subjects and several also reported positive interactions with the therapist and others during music therapy. These findings support the use of music therapy for hospitalized adolescents with cystic fibrosis and suggest that music therapy has benefits that are encountered and recognized by these patients. The results of this study will be useful for music therapists, educators and other health professionals in developing a better understanding of the benefits experienced during music therapy by the hospitalized adolescent with CF.
CHAPTER 1: INTRODUCTION

Cystic fibrosis (CF) is an inherited disease that affects many systems, primarily the gastrointestinal system and the lungs (Cutting, 2000; Fiel, 1993; Harris & Super, 1995). Complex and time-consuming therapeutic regimes, regular antibiotic treatments and frequent hospitalizations are a regular part of the treatment process (Bluebond-Langer, Lask, & Angst, 2001; Hopkin, 1998). Music therapists often address issues of regression, anxiety, stress, diminished self-esteem, decreased socialization and adjustment to unusual routines that chronically ill children frequently face during hospitalization (Brodsky, 1989; Dun, 1995). This study examined the perceptions acquired from six patients aged 12-18 who received individual music therapy sessions while hospitalized for CF. Two of the subjects’ sessions were dyads as their siblings, who were also hospitalized with CF, actively participated in their music therapy sessions.

Although there have been many studies reporting the changes music therapists observe in the hospitalized child during a music therapy session (Robb, 2000), little information is known about these effects as reported by the children themselves. Most studies involving music therapy and the hospitalized child currently available are quantitative. There appears to be very little information available reporting the effects of music therapy on children with cystic fibrosis, especially during hospitalization.

In 1996, Furman stated that many previous studies concerning medical patients address the physiological benefits of music (as cited in Goodman, 2000) but there are many other potential benefits music therapy has to offer the hospitalized
medical patient. Goodman’s qualitative study on the perceived effects of the mental health of adult medical patients showed many positive results. Hospitalized adult patients reported effects of music therapy such as “promoted positive affect; calming, relaxing, relieved stress; altered thought content; provided interpersonal relationship; relieved boredom, passed time; provided self-expression” (Goodman, p. 33). As described in a report compiled by Hibben, a 17-year old patient with sickle-cell anemia explained the benefits of music therapy as providing distraction from pain and allowing “him to release tension, gain control, fall asleep” (as cited in Goodman, p.18).

The limitations of this study include the researcher as interviewer, the number of previous music therapy sessions the child had, the child’s previous relationship with the music therapist, the varying techniques used during the different sessions, and the severity of illness. Implications for future research include comparison of the child’s reports with the observations of the music therapist, reproducing the study on a larger scale while expanding the parameters to include children with similar diagnoses, and developing a survey based on the results of future research. Replication of this study may also include focus on issues including chronic illness, isolation, quality of life or the therapeutic relationship. Other considerations for research comprise increased attention to coping styles, adherence to self-care, respiratory function, sibling and family therapy, and development of additional treatment methods.

The purpose of this qualitative study was to determine the effects of music therapy on hospitalized children with cystic fibrosis. The objective of this study was
to accumulate preliminary descriptive data on how music therapy affects hospitalized children with cystic fibrosis physically, psychologically, and interpersonally, based on their self-reports after three music therapy sessions. During an open-ended personal interview subjects were asked to report the effect music therapy had on their physical state (activity level, energy, breathing, pain), cognitive state (memories, thoughts of being somewhere else, imagery/associations), emotional state (including fear, boredom, loneliness, mood change and the ability to discuss their feelings), and self-perception (including feeling or thinking differently about one’s self, things, the future, and hospitalization). All of these response areas are often affected during hospitalization. Allowing the subjects to respond freely and spontaneously during the interview process facilitated identification of new areas of focus previously not known to the researcher.

The findings will be used to inform music therapists and educators how the hospitalized child with cystic fibrosis perceives the effects of a music therapy session so that specific methods may be further developed. By obtaining extensive information directly from the child about his or her music therapy experience, the therapist develops a better understanding about the many ways the individual personally experienced music therapy. The in depth information gleaned from the interviews in this study will help the therapists when they work with these patients in the future to develop practical music therapy goals and treatment methods. The patients will benefit from therapy that is most appropriate for their individual needs. The findings may also be used as the foundation for the development of outcome research.
CHAPTER 2: LITERATURE REVIEW

Cystic Fibrosis

Cystic fibrosis (CF) is an inherited disease that affects many systems, primarily the gastrointestinal system and the lungs (Cutting, 2000; Fiel, 1993; Harris & Super, 1995). It is an autosomal recessive disease, so a child has a one in four chance of inheriting CF when both parents carry the defective gene and a sibling of a child with CF has a one in four chance of having the disease as well. The probability for half siblings to inherit the disease is also greater when compared to the general population (Harris & Super; Hodson & Geddes, 2000). Every year in the United States, approximately one in 3,500 children is born with CF and roughly 30,000 people in the United States currently live with the disease. Although CF affects all ethnic groups it is much more common in Caucasians than other races (Hopkin, 1998) and is “the most common fatal recessive genetic disease among white people” (Gjengedal, Rustøen, Wahl, & Hanestad, 2003, para. 2). The frequency of CF in live births is 1 in 2,500 for Caucasians, 1 in 17,000 for African Americans and 1 in 90,000 for Asian Americans (“Cystic Fibrosis Foundation”, 2005). The reason for the high incidence in the Caucasian race is unknown (Bluebond-Langer, Lask, & Angst, 2001). CF is equally prevalent among males and females (Harris & Super).

Genetics

Symptoms of CF were initially characterized as separate manifestations of various illnesses related to the respiratory and gastrointestinal systems however it was not until 1938 that CF was first recognized as a distinct disease in children. In 1989 the gene responsible for CF, known as cystic fibrosis transmembrane conductance
regulator or CFTR, was isolated (Gjengedal et al., 2003; Harris & Super, 1995; Hodson & Geddes, 2000; Hopkin, 1998).

“Mutated forms of the gene disturb the transportation of salt and water across cell membranes and lead to production of unusual thick mucus that blocks bodily passages, particularly in the digestive and respiratory systems. The increased volume of thick secretion gives favorable conditions for infections that result in recurrent airway inflammations and bronchiectasis. Likewise, the pancreas channel will be affected by sticky fluid, which may result in fibrosis and destruction of the gland. Pancreatic insufficiency may lead to malabsorption and diabetes.” (Gjengedal et al., para 2).

**Diagnosis**

Prenatal diagnosis to exclude or confirm CF can be made through “chorionic villus sampling or amniocentesis” (Hodson & Geddes, 2000, p. 179) for pregnancies known to be at increased risk because of carrier status of the parents or family history. At risk couples are also able to use alternative methods to pre-screen embryos before implantation. In both scenarios it is important to follow up with post-natal testing as well (Hodson & Geddes; Hopkin, 1998). To date there are over 1,000 mutations of the CF gene (“Cystic Fibrosis Foundation-What is CF?”, 2005) and since not all mutations of the gene are known, screening may potentially miss undiscovered variants of the CFTR gene. The large number of mutations is one of the reasons for variation in disease manifestation and progression (Harris & Super, 1995; Hodson & Geddes; Hopkin).

Although presentation of CF varies, the majority of affected individuals first experience symptoms as children. In the United States most patients with CF are diagnosed by the age of one, however about 10% of the cases are diagnosed after the age of ten. The illness in some individuals who exhibit less severe manifestations of
symptoms may not be identified until adolescence or early adulthood (Gjengedal et al., 2003; Hodson & Geddes, 2000). In newborns with CF, meconium ileus, a severe intestinal obstruction caused by the thickened mucus secretions characteristic of CF, may be one of the first indicators of the disease. Newborns may also appear jaundiced due to bile ducts becoming clogged with mucus. Symptoms leading to a suspected diagnosis of CF include chronic bronchitis, frequent pneumonia, chronic cough, difficulty digesting food, fatty stools, failure to thrive (in children), inability to gain weight despite large appetites, intestinal obstruction, rectal prolapse, azoospermia (males), and digital clubbing. The common nature of many of the symptoms can lead to difficulty in diagnosis and misdiagnosis (Harris & Super, 1995; Hodson & Geddes, 2000; Hopkin, 1998). “The sweat test remains the ‘gold standard’ for confirmation or exclusion of the diagnosis of CF” (Hodson & Geddes, p. 179) and is performed on patients with a family history or with a clinical presentation that indicates a possible diagnosis of CF. Since CF is an inherited disease it is not contagious nor can it be outgrown, therefore care is focused on treatment and preserving quality of life (Hodson & Geddes).

Clinic

Optimal care for patients with CF involves treatment at a CF clinic where patients receive focused care from professionals specializing in the treatment of CF, including physicians, nurse practitioners, nurses, dieticians, pulmonary function specialists, physiotherapists, psychologists/psychiatrists, and social workers. Patients and their families can be assured of receiving the most advanced care provided by the expertise of a trained and experienced staff. Continuity of care, supportive contacts
with staff and other families, and opportunities to participate in research studies are some of the other advantages of the clinics. Disadvantages may include knowing affected people who die and contact with patients with more severe forms of the disease. Precautions taken usually keep the risk of cross-infection at a clinic low. A typical clinic visit generally involves a comprehensive physical exam, recording the patient’s weight and height, and a pulmonary function test (PFT) to measure lung function. A throat swab or sputum sample may be obtained to check the current bacteria flora in the lungs, especially if there is a sign of infection. Any necessary treatment and follow up care including hospitalization is managed by the team at the CF clinic (Harris & Super, 1995; Hopkin, 1998).

Treatment

Treatment currently focuses on alleviating symptoms so that people with CF can maintain reasonably normal lives. Basic treatment concentrates on problems with breathing and digestion. Enzyme supplements are taken with meals and snacks to facilitate digestion and caloric intake and nutritional needs are carefully monitored. Supplemental nutrition may be provided as needed orally or through tube feedings (Harris & Super, 1995; Hopkin, 1998; Walsh, Cassano, Manangan, Sinkowitz-Cochran, Jarvis, 2002).

In CF, respiratory failure is the most common cause for morbidity and mortality. The excess mucous that collects in the lungs of CF patients causes difficulty with respiration (Cutting, 2000; Fiel, 1993; Harris & Super, 1995). Additional problems associated with CF’s effects on the lungs include “breathlessness, chest wall stiffness... and reduced exercise tolerance” (Pryor &
There are currently many medical interventions used to treat lung problems in patients with CF. It is recommended that chest physiotherapy begin as soon as a diagnosis is confirmed (Grasso, Button, Allison, & Sawyer, 2000; Pryor & Weber, 2000). To help clear their airways, patients are treated with airway clearance techniques which include chest percussion, postural drainage, and special breathing exercises. Mucolytic agents (drugs that reduce the thickness of airway secretions) and bronchodilators (medications taken into the lungs through inhalers or nebulizers that help open the patient’s airways) are used in the treatment of the lung disease associated with CF (Marshall, Rosenfeld, & Ramsey, 2000). As a result of deeper breathing during physical exertion, exercise is important in order to improve lung function and decrease chest wall stiffness (Pryor & Weber). Patients with severe lung disease may require supplemental oxygen, and as a final resource, some may opt for a double-lung transplant (Fiel 1993; Madden, 2000).

“Chronic pulmonary infections with Staphylococcus aureus, Haemophilus influenzae, Pseudomonas aeruginosa, or Burkholderia cepacia (B cepacia) complex frequently are associated with increased morbidity and mortality rates in patients with CF” (Walsh et al., 2002, Introduction para. 1). Due in part to antibiotic resistance, B cepacia is one of the most dangerous infections for people with CF. It can be transmitted via casual contact and is carried on the body and clothes of individuals and objects for several hours after contact. Therefore B cepacia can be spread by both carriers and non-carriers but it is harmless to individuals without CF. Treatment is aimed at suppression of the infection and improvement of clinical symptoms, but once infected, eradication of B cepacia is virtually impossible. Recommendations to
prevent transmission of B cepacia include following appropriate infection control procedures in all health care settings and separating B cepacia complex-colonized patients with CF from non-colonized patients (Walsh et al.; Hodson & Geddes).

Despite advances in understanding of the genetics and pathophysiology of CF, a curative treatment is not yet available. Patients have to go through complex and time-consuming therapeutic regimes and regular antibiotic treatments. Duration and frequency of hospitalizations for infections and ‘tune-ups’ to optimize health vary due to disease severity but are a regular part of the treatment process. Because of improved treatment in recent years, the survival rate of patients with CF has increased dramatically, which means that the number of adult people with CF is also increasing. For unknown reasons, poorer prognosis for female patients appears universal (Bluebond-Langer et al., 2001; Hopkins, 1998; Staab et al, 1998). The average life expectancy for a patient with cystic fibrosis is 30 to 40 years, with a median survival of around 35 years for babies born in 2005 (“Cystic Fibrosis Foundation”, 2005).

Psychological Issues of Cystic Fibrosis

Progress made in CF research and treatment in recent years has impacted life expectancy and quality of life as well as the potential for a cure, therefore it is important to look at the most recent data, as much of the information in some of the earlier studies has become outdated (Bluebond-Langer et al., 2001).

Infancy and Pre-school

Even though CF is usually diagnosed early in life, there appear to be few studies done on the psychological impact of CF on children and their families during the infant and pre-school years. Data presented by Simmons and Goldberg “indicates
that infants and pre-schoolers with CF generally do well emotionally, developmentally and physically. Their mothers do report stress and depressive symptoms as they attempt to cope with the strain of managing their expanding caregiving role” (as cited in Bluebond-Langer et al., 2001, p. 121). There are several subgroups that may be at risk for developing problems related to their attachment difficulties, poor response to treatment, and behavior problems. It is important that these potential dilemmas be identified early and preventative interventions be sought to avoid future problems and to provide for the best possible outcome for both the child and caregivers (Bluebond-Langer et al.; Staab et al, 1998).

**School Age**

All children deal with various challenges related to fitting in with their peers. These difficulties may be magnified for the child with CF “who is often smaller, looks younger than age mates, and whose cough cannot be disguised” (Bluebond-Langer et al., 2001, p. 131). The main issues school age children with CF face according to self-reports are “feeling different, school issues and peer relationships” (Bluebond-Langer et al., p. 131). Children with CF describe struggling with having to explain their illness and treatments to others. They define their cough and taking medications as what most differentiates them from their peers, especially when others demonstrate awareness of their symptoms and treatment (Bluebond-Langer et al.). Adjustment issues, anxiety and feelings of difference have been documented in many studies as a significant issue among children coping with CF and other chronic illnesses (Bluebond-Langer et al.; Thompson, Gustafson, Gil, Godfrey, & Murphy, 1998). Children with CF appear to use ‘adaptive denial’ as a strategy to cope with
their illness by maintaining a positive outlook, focusing on activities of daily life, and only talking about CF when they are forced to. This coping mechanism has also been seen in families of children with CF and other chronic illnesses (Bluebond-Langer et al.).

Healthy peer relationships are important during this age. Research provides conflicting information as to the impact of CF and other chronic illnesses on the school age child’s social competence and developmental tasks. Since children with CF may miss more school than their healthy peers they are at greater risk for developing difficulties in these areas (Bluebond-Langer et al., 2001; Thompson et al., 1998). Preventative measures to minimize absences, limit restrictions and de-emphasize the child’s differences can be taken through careful monitoring by parents, school personnel and clinicians. Friendships with other children with CF can also provide unique support. It is often during the school-age years where many children become more involved in their self-care and management of their illness as they begin to develop a better understanding of their disease (Bluebond-Langer et al.).

Adolescence

Adolescence is a time for change and growth, physically, sexually and emotionally. This phase of life can be challenging and complicated even for those in ideal health. Healthy adolescents use this time to seek their own identity, establish their independence and test boundaries by participating in risk-taking behaviors. This period of time poses more difficulties for adolescents with chronic illnesses such as CF (Bluebond-Langer et al., 2001). Complicating the situation for the adolescent with CF are the many physical, social and psychological challenges they must also
face. “They must contend not only with physical limitations that make them different from their peers, but also with their parents’ reluctance to allow them to function independently and to make choices that may compromise their health” (Bluebond-Langer et al., p. 140). For the patient with CF these are the years when their health may begin to deteriorate. Adolescents may need to spend more time doing treatments and take on increasingly more responsibility for these treatments. They may require more frequent hospitalizations and have problems with malnutrition. Puberty is often delayed and the impact of CF on reproductive ability is addressed including issues of sexual function and infertility for males and the impact of pregnancy on disease process for females (Bluebond-Langer et al.; Bolyard, 2001).

Body image, self-esteem, sexuality and all issues surrounding quality of life and development of a positive self concept are of increasing significance for individuals with CF, especially during adolescence (Bolyard, 2001; Esmond 2000). Sawyer, Rosier, Phelan and Bowes (1995) suggest that although adolescent boys appeared similar to their healthy counterparts in self-image scores, adolescent girls had significantly lower scores in the area of body and self-image when compared to healthy controls. Results from a study examining adolescent independence appeared favorable except in the areas of social activities and sexuality where adolescents with CF may have scored lower than their healthy counterparts due their delayed puberty and short stature (Bluebond-Langer et al., 2001). Adolescents with CF often face additional challenges in developing a positive body image and sense of self due to noticeable differences such as their small stature, barrel shaped chest, clubbed fingers, chronic cough and access devices for necessary treatments (Bluebond-Langer et al.;
According to one study, the chronically ill were less likely to take part in typical risk-taking behavior than their healthy peers. Teenage rebellion in individuals with CF often manifests as a decline in adherence to treatment and can be very difficult for both patient and family (Bluebond-Langer et al.; Esmond).

Socialization and peer relationships are crucial at this age. Primarily due to B. Cepacia and other easily transmittable infections, social contact between patients with CF is often limited. Organizations have been working on strategies to encourage support within the community such as newsletters, media and the internet to help patients maintain communication while avoiding the risks associated with face to face contact (Bluebond-Langer et al., 2001; Walsh et al., 2002).

“Studies of adolescents and adults with CF tend to emphasize that this group has a good educational and work record when compared to the general (healthy) population” (Bluebond-Langer et al., 2001, p. 141). According to the 1990 ‘Trent study’, top concerns expressed by these individuals were, in order, “possibility of dying at a young age, breathlessness, keeping a job, coughing up blood [and] possibility of not having children” (as cited in Bluebond-Langer et al., p. 142).

Psychological Impact of Cystic Fibrosis

Results from several studies in the United States indicate that up to 2.5 percent of children and up to 8.3 percent of adolescents suffer from depression (“About teen depression”, n.d.; “Depression research”, 2006). “An NIMH-sponsored study of 9 to 17 year-olds estimates that the prevalence of any depression is more than 6 percent in a 6-month period, with 4.9 percent having major depression” (“About teen depression”, fact sheet para. 1). Among children and adolescents, chronic physical
illness is considered a risk factor for developing depression (“About teen depression”; Sawyer, et al. 1995). Pless (1984) found that “children with chronic illness have a risk for psychological adjustment problems that is 1.5 to 3 times as high as their healthy peers” (as cited in Thompson et al., 1998, p. 122).

According to the 2004 Annual Data Report, one of the complications of CF is depression. “This is a common complication of many chronic diseases. People with CF, their families and caregivers need to be aware of this complication, so that diagnosis and treatment can be started early” (“Cystic Fibrosis Foundation”, 2005, p. 9). Approximately five percent of children age 11 to 17 reported experiencing symptoms of depression with more than 13 percent of adults suffering from these symptoms (“Cystic Fibrosis Foundation”). Staab et al. (1998) employed a questionnaire to measure the health related quality of life (HRQOL) of patients with CF and their families. The study concluded that “cognitive and behavioral factors such as health perception and ways of coping play an important part in HRQOL in patients with CF and their families” (Staab et al., Discussion, para 3). The report emphasized the importance of providing psychological support and assistance with coping skills, especially early on in the course of the disease (Staab et al.). Continued support is also important as adolescents seek independence during the transition to adulthood. Individuals with CF contend with additional factors and may still need to rely on their parents emotionally and physically due to limitations from their illness (Esmond, 2000).
Psychological Effects of Hospitalization

Hospitalization can be a particularly difficult and stressful time for anyone, especially children (Becker, 1976, as cited in Brodsky, 1989). “Several authors (Becker, 1976; Froehlich, 1984; Schwankovsky & Guthrie, 1982) point out that children’s reactions to hospitalization often include anxiety, withdrawal, regression, and defiance” (as cited in Brodsky, p. 17). While in the hospital, the child is in an unfamiliar place, away from home, family, friends, school and their daily routine. They must learn to rely on others and follow restrictions on their activities (Jones, 1991, as cited in Dun). These stressors “exacerbate feelings of vulnerability, loss of self-control, and various stages of regression” (Becker, as cited in Brodsky, p. 18).

Denshire and Bennett (1985) emphasize that adolescents who have chronic illnesses involving repeated hospitalizations are “especially vulnerable and at risk for poor self-esteem, distorted body image, sexuality concerns, familial over-protection, and lack of peer-group interactions” (as cited in Brodsky, p.18).

Many options are available to patients with CF to help them manage the complex psychological issues they may face during their hospitalization. Social workers are generally available to provide guidance to both the patient and family/caregivers in managing all aspects of their care (Harris & Super, 1995). Patients may receive referral to and treatment by a psychologist (Bluebond-Langer et al., 2001). Art therapy (Colwell, Davis & Schroeder, 2005; Epping & Wilmuth, 1994; Prager, 1993; Sundaram, 1995) and dance/movement therapy (Goodill & Morningstar 1993; Koshland & Curry, 1996) are cited in the literature as supportive psychological services available to hospitalized children and adolescents with CF. In
addition, several other therapeutic services are available during pediatric hospitalization including child life services (American academy on pediatrics, 2000; Bishop, Christenberry, Robb & Rudenberg, 1996; Froehlich, 1996b; Rudenberg & Royka 1989), therapeutic play (Kneisley, 1996), puppet and drama therapy (Brounley, 1996), and bibliotherapy and creative writing as expressive arts (Froehlich, 1996a).

Music Therapy

Music therapy is also one of the supportive psychological services available to help children with CF cope with their illness during hospitalization.

“Music therapy is an established health service similar to occupational therapy and physical therapy. It consists of using music therapeutically to address physical, psychological, cognitive and/or social functioning for patients of all ages. Because music therapy is a powerful and non-invasive medium, unique outcomes are possible. In addition to its applications with hospital patients, music therapy is used successfully with persons of all ages and disabilities” (“Music Therapy”, 2001, para. 1).

Music Therapy and Hospitalized Children

Music therapy methods used in the hospital environment may include improvisation, song writing, metaphoric play, music or song choice, listening, lyric discussion or analysis, and relaxation as well as other forms of active music making and various additional techniques. An emphasis is frequently placed on the therapeutic relationship where trust and support are of primary significance (Edwards 1999; Jacobowitz 1992; Robb 2000).
“...A child has opportunities to maximize coping skills in relation to the demands of hospitalization and treatments. It is proposed that the role of the therapist, as a person not associated directly with medical treatment or procedures, along with the familiar medium of music, provides a calming and sympathetic presence (Chetta, 1981; Edwards, 1995; Loveszy, 1991)” (as cited in Edwards, 1999, p. 71).

The specific needs of patients are emphasized through assessments, treatment plans, individualized goals and follow-up care. Therapy is provided in individual or group sessions and type of treatment may vary depending on the theoretical background of the music therapist (Maranto, 1996; “Music Therapy”, 2001). Fostering independence through inclusion in all aspects of treatment and offering family support as needed are important ways to promote normalcy and provide care for the whole patient (Bishop et al., 1996; Lathom-Radocy, 2002). Considerations always need to be taken in the hospital environment to follow specific guidelines regarding universal precautions, infection control, and any other regulations particular to a setting so that the health of the patient remains the primary focus (Lathom-Radocy, 2002).

Music therapy has been proven to enhance the well being of sick children, both physically and emotionally. Positive experiences with exercise, deep breathing and increased range of motion are some of the benefits of music therapy as determined in various studies (Dun 1995, Griggs-Drane 1999, Rudenberg & Royka 1989). Among chronically ill children, music therapy is often used to promote greater self-esteem, better social functioning, improved mood, and decreased perception of pain (Klein, & Winkelstein, 1996; Lane, n.d.; Lane, 1994; Loewy, ed. 1997; Loewy, 1999b; Robertson, 1992). ‘Walter’, a 17-year old patient with sickle-cell anemia poignantly describes his experience to his therapist JoAnne Loewy
(1999a) explaining how the music therapy provided him distraction from pain, allowing his “mind to go somewhere completely different” (p. 73). He described how he benefited from the release of tension, and the use of imagery and expressed his appreciation for the therapists who would “sing [him] off” (Loewy, p. 75) providing his favorite music that helped him relax and eased his pain.

Studies involving the effects of music therapy on hospitalized children have shown positive results (Robb, 2000; Boldt, 1996). Music therapy has been used successfully with hospitalized pediatric patients in the management of anxiety (Bishop et al., 1996; Dun, 1995; Edwards, 1999) and can support the use of music as a powerful avenue for expression without necessitating the use of words (Lane, 1994; Tyler, 1996). As documented in music therapy literature on pediatric hospitalization (Brodsky, 1989; Colwell et al., 2005; Lathom-Radocy, 2002; Robb, 2000; Robertson 1992; Rudenberg & Royka, 1989) music therapy provides opportunities to improve self-expression and coping skills, decrease isolation, prevent regression, and promote feelings of normalization.

Robertson’s 1992 study surveying music therapists lists anger, feelings of helplessness and increased dependency as some of the concerns facing hospitalized children. In the study, singing familiar songs, improvisation, relaxation, imagery and movement were the most prevalent methods chosen by the therapists to address these and other issues facing their patients. The most common goals reported were decreasing anxiety and distress, promoting creative expression, increasing sensory stimulation, and improving coping skills.
In a comprehensive review of the literature Maranto (1996) describes positive physical, psychological and behavioral responses to music therapy among a wide variety of hospitalized patients. She details studies using a range of patients, interventions and dependent variables and includes summaries of results categorized by patient groupings. Her review emphasizes the progress made in the field and stresses the need for continued research in the area of music therapy in the medical environment.

*Music Therapy and Cystic Fibrosis*

Limited information is available about the influence of music therapy on patients with cystic fibrosis. In a study involving infants and toddlers with cystic fibrosis, parents reported that listening to music was shown to have a positive effect on their children’s feelings related to chest physiotherapy. Two groups of patients were involved. During chest physiotherapy, the control group used no music some times and a tape of familiar songs (the same for each child) other times. The treatment group listened to a treatment tape created by the music therapist specifically for the study. Evaluations completed by the parents indicated a statistically significant improvement in the parents’ and children’s enjoyment of chest physiotherapy while using the treatment tape. There was no change in the parents’ or children’s enjoyment with the use of the tape of familiar songs. Results indicated that in order to improve the subjects’ reaction to and acceptance of the music, it may be beneficial to specifically tailor the music to an individual or a certain group (Grasso et al., 2000).
Preliminary data describes the potential of music therapy involving wind instruments to positively affect the quality of life of patients with CF. Emphasis is placed on the importance of taking care in choosing an instrument that will optimize success for the player and provide potential for use in exercising the lungs. Playing a wind instrument may not only give the individual with CF an opportunity to exercise their lungs outside a clinical setting, but it may also provide them with a sense of achievement and opportunities for socialization by playing in ensembles (Griggs-Drane, 1999). Ellen Griggs-Drane states that “the use of music to enhance correct breathing techniques with pulmonary patients has been found to be an effective, nontraditional intervention that has resulted in emotional, physiological, and physical benefits” (pp. 129-30).
CHAPTER 3: METHODOLOGY

Design

The objective of this study was to accumulate preliminary descriptive data on how music therapy affects hospitalized children with cystic fibrosis physically, psychologically, and interpersonally, based on their self-reports after three music therapy sessions. The findings may be used to inform music therapists and educators how the hospitalized child with cystic fibrosis perceives the effects of a music therapy session so that practical music therapy treatment goals and methods may be further developed. The results may also be used as the foundation for the development of outcome research.

This study employed a phenomenological interview design. Typically, a phenomenological study is one in which “human experiences are examined through the detailed descriptions of the people being studied” (Creswell, 1994, p. 12). In a phenomenological study, sample size should be approximately six participants (Denzin & Lincoln, Eds. 1994; Mertens, 1998). An open-ended personal interview style was chosen, as the conversational format allows subjects to respond freely and spontaneously. This method was utilized to obtain as much insight as possible into the perspective of the patient by providing them with ample opportunity to express their own ideas using their own words. This type of spontaneously gathered information can often be valuable in the formulation of new hypotheses (Oppenheim, 1992).
Description of Subjects

Six subjects were enrolled in the study over a time period of seven months. Six other subjects were also recruited during this time period. Four of them declined participation in both the study and music therapy, two others agreed to the study but unanticipated discharge from the hospital prevented their participation.

Subject Selection Procedures

Subjects were required to be ages 12 to 18 when initially enrolled in the study. Subjects needed to have a clinical diagnosis of cystic fibrosis, be hospitalized throughout the course of the study and have a referral for music therapy services. Previous music therapy experience did not exclude patients from the study. It was necessary for the subjects to be physically able to tolerate music therapy sessions and the interview. Due to the nature of the questions being asked, subjects’ education levels were required to be developmentally appropriate. Subjects were required to speak fluent English and be able to answer simple questions similar to those in a routine pediatric interview or that might normally take place during a music therapy session. These determinations were made, upon initial contact with each potential subject, by the music therapist who conducted the therapy sessions. No limitations were made in regard to race/ethnicity or gender. There were no control subjects and no advertisements to recruit research subjects. Random selection did not apply because “qualitative inquiry typically focuses in depth on relatively small samples… selected purposefully” (Patton, 1990, p.169).
Subject Recruitment and Consent Procedures

It was necessary to first obtain Institutional Review Board (IRB) approval from The Children’s Hospital of Philadelphia (CHOP) and then from Drexel University. Due to variations in protocol the approval from CHOP’s IRB was expedited however Drexel’s IRB protocol mandated full review due to the involvement of children. The study took place at The Children’s Hospital of Philadelphia. Every attempt was made to recruit all eligible subjects during the time period of the study. Upon referral to music therapy the music therapist performing the intervention met with each patient (and their parents or primary caregiver if under 18) to explain the study and requirements for participation. Patients who agreed to participate were then asked to read and sign appropriate consent and assent forms (See Appendix A for examples of consent and assent forms). If patients did not wish to participate in the study they were still given the option to receive music therapy services.

Clinical Procedures

Each subject received three music therapy sessions that were approximately 30 to 60 minutes in duration on three separate days. Whenever possible, sessions were scheduled ahead of time. The three sessions took place over a period of approximately one to two weeks depending on the participants’ and therapist’s schedules. These sessions were audio taped. At the conclusion of the third session, the music therapist contacted the interviewer who then communicated directly with the subject and/or caregiver by phone to schedule an interview. Interviews were conducted as close to the end of the third music therapy session as possible. After the
interview was complete, the subject’s involvement in the study was finished, but he/she was given the option to continue to participate in music therapy for the remainder of his/her hospital stay.

Protocol

The music therapist, Patrick Lipawen, was the therapist on staff at The Children’s Hospital of Philadelphia. He is a Master’s level, board certified, music therapist with several years of experience working with hospitalized children. Music therapy sessions were designed to meet the individual needs of the patients, including assessments when needed and treatment plans. Some examples of music therapy processes may have included improvisation, musical and verbal interaction with the music therapist, playing musical instruments, singing, listening to music, composing music and movement to music. Since infection control protocol prevents patients with CF from leaving their rooms except for essential medical procedures and tests, music therapy sessions were conducted in each subject’s room. The therapist also wore a gown and gloves during sessions per protocol. The interviewer was the researcher but not the music therapist. This was to allow subjects to answer questions freely and honestly without the presence of the music therapist.

Data Collection

The interviews were conducted in each subject’s room and the interviewer wore a gown and gloves per infection control protocol. Family members and other hospitalized siblings were present during some of the interviews. Every attempt was made to keep the environment free from distractions, however due to the nature of the hospital setting, some interruptions from medical personnel and other staff were
unavoidable. All interviews were audio taped and lasted from 10 to 40 minutes in duration.

The interview was conducted in an open-ended style. The interview questions and the style of the interview were based on Goodman’s design utilized in a music therapy study involving hospitalized adult patients. Goodman “used the methods described by Oppenheim (1992) [whose] ideas concerning order and flow and his conversation-like approach seemed to create an interview in which the patients would feel most comfortable” (Goodman, 2000, p. 24). This methodology was also practiced successfully in a music therapy study by Lu (2002) while researching “the effects of fetus directed singing on at-risk pregnant women”. Interview questions were carefully constructed and worded to be easily understood by the young subjects. The interviewer initially asked general open-ended questions then proceeded to more specific questions as needed following the lead of the subject. The interview consisted of questions about the subject’s previous musical experiences (including music therapy), the content of music therapy sessions, and the perceived effects of music therapy on their body, thoughts, feelings, and self-perception. Subjects were also asked some basic questions about themselves including family information, CF, and hospitalization. The interview concluded with the interviewer expressing appreciation for the subject’s involvement in the study (See Appendix B for interview questions).

**Data Analysis**

The interviews were transcribed verbatim and analyzed using methods described by Weiss (1994) in Learning from Strangers. The type of analysis was
issue focused in that the study was designed to generate information that would “describe what has been learned from all respondents in their situation” (Weiss, p. 153).

Data analysis followed the four steps described by Weiss (1994) and implemented by Goodman (2002). In the first step, coding, responses were linked together and coded, forming several themes. During the second step, sorting, specific responses were extracted and grouped with like responses into similar categories. Local integration, the third step, consisted of further organizing responses and defining each main theme or grouping. Finally the process of inclusive integration provided coherence by logically connecting the themes to form the big picture (Goodman; Weiss).

The following steps demonstrate the data analysis process executed during the study:

a) Coding: Charts were created using the predetermined groupings established by formulating the interview questions directly into themes. For example, the question “Did you notice any changes in your body during the music?” became the theme ‘body’. All responses were linked specifically to these themes and charted. Freely generated answers were classified under the theme which initially stimulated the response.
b) Sorting: Responses in the chart were color coded by identifying key words or phrases with similar content. For example the key word ‘new’ was established. An example of a phrase was ‘positive to negative mood change’ (also recognized with key words such as ‘mad’ and ‘happy’). Through this process the original themes were more clearly organized and developed into categories. These categories were refined using topics from the original themes as well as new topics which emerged as a result of the subjects’ responses. Some examples of the categories included self-discovery, mood and relaxation.

c) Local integration: Category content was organized as responses were re-evaluated and placed into categories based on criteria defined in the operational definition of variables. For the purpose of this study, if a response met the criteria for more than one category it was grouped only in the category in which it best fit.

d) Inclusive integration: The categories were grouped together based on content into the major domains of cognitive responses, physical responses, emotional responses, and interpersonal experiences. This provided an organized, comprehensive account of the music therapy experience as described by the subjects.
Operational Definition of Variables

For the purpose of this study the following definitions have been generated and assigned to major domains and descriptive categories.

- **Cognitive Response:** Any kind of thinking, assessing, or evaluating related to personal observations or appraisal of the self
  - Self-discovery: Personal awareness of the value of new experiences (to enhance one’s own development)
  - Self-confidence: Personal realization of one’s own growth, capabilities; may involve mastery experiences
  - Change in Perspective: Ability to think or feel differently about one’s self; often insight oriented
  - Distraction: Allows person to focus on something outside their present situation
  - Extra Musical Associations: Some part of the musical experience reminds a person of something outside the immediate music

- **Emotional Response:** Any feeling, affective change generated from the music therapy experience
  - Mood: Personal description of feelings, emotional state
  - Self-expression: Personal process where music therapy provides a unique way for one to express him/herself
  - Anticipation/Reduction of isolation: Meaningful experience that provides something to look forward to, increases personal contact, decreases loneliness, and/or reduces boredom
- Peak experience: “Moments of highest happiness and fulfillment”
  (Maslow, 1968, p. 73)

  - Physical Response: Aesthetic use of the body; any effect on the body that the person noticed
    - Relaxation: Reduction in personally perceived stressors/negative feelings
    - Exercising: Use of muscles, movement in response to music
    - Energy: State of power, vigor
    - Breathing: Any effect on the lungs or respiratory system
    - Pain: Physical discomfort

  - Interpersonal Experience: Personal experience involving other people; includes live events as well as thoughts associations, memories etc.
    - Therapeutic Relationship: Personal connection established with the music therapist; often fostered through trust and support
    - Interpersonal Associations: Thoughts and memories related to persons not physically present during the music therapy sessions
    - Family Relationships: Significant connection with family members during the music therapy sessions
    - Interaction with Others: Significant events involving other persons during the music therapy sessions
CHAPTER 4: RESULTS

Introduction

In order to provide an understanding of the subjects’ reactions to the music therapy this chapter includes the background of each subject according to their reports and interviewer observations. These brief histories contain subjects’ age, gender, race, data on siblings, length of hospitalization until time of interview, previous hospitalizations, and music and music therapy experience. (See Table 1: Subject Information on p. 31) The major findings section then encompasses subjects’ descriptions of their music therapy sessions obtained during the personal interviews and compiled categorically.

Background of Each Subject

Subject #1 is a 15 year old Caucasian male with one sibling, a 10 year old brother who does not have CF. His length of hospitalization at the time of the interview was three weeks, he said he “can’t even count” the number of times he was previously hospitalized, and he is infected with B Cepacia. He played trumpet in school for one year but indicated he felt it “wasn’t too good for [him] to play because of [his] lungs”. Subject #1 also described his experience playing in a band with several friends. He revealed this information spontaneously over the course of the interview, not as a result of direct questioning about musical experience. “At home I play with this little tiny band…we play like maybe once a month or something so nothing big… **** plays the drums, **** is a singer and **** is another guitarist. I do more like background music”. He proceeded to describe how they have beat
Table 1: Subject Information

<table>
<thead>
<tr>
<th>Subject</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>Siblings</th>
<th>CF in Siblings</th>
<th>Current Hospital LOS</th>
<th>B Cepacia</th>
<th>Previous Hospitalizations</th>
<th>Previous Music Experience</th>
<th>Prev MT</th>
<th>When/Where</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>15</td>
<td>Male</td>
<td>Caucasian</td>
<td>10y M</td>
<td>None</td>
<td>3 weeks</td>
<td>Yes</td>
<td>“can’t even count”</td>
<td>Trumpet for a year in school Guitar in band w/ friends</td>
<td>Yes</td>
<td>Many times we’ve had sessions. All with Patrick, one time w/ student. (many ?x)</td>
</tr>
<tr>
<td>#2</td>
<td>12</td>
<td>Male</td>
<td>Caucasian</td>
<td>8y F 9y M</td>
<td>8y F (at sessions)</td>
<td>1 week and 4 days</td>
<td>No</td>
<td>none</td>
<td>None, watches music videos</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>#3</td>
<td>13</td>
<td>Female</td>
<td>African American</td>
<td>5m F 11y M 18y F 20y F 29y F</td>
<td>11y M (at sessions)</td>
<td>2 weeks</td>
<td>Yes</td>
<td>“like, I’d say about 9 or 10”</td>
<td>Making music therapy video</td>
<td>No</td>
<td>The video session (1x)</td>
</tr>
<tr>
<td>#4</td>
<td>18</td>
<td>Female</td>
<td>Caucasian</td>
<td>16y F 19y F</td>
<td>16y F 19y F</td>
<td>2 weeks and 4 days</td>
<td>Yes</td>
<td>“Too many to count”; Early age about every 2 years then past few years 2-3 times per year</td>
<td>Extensive Piano, voice, chorus, family music ties</td>
<td>Yes</td>
<td>Previous hospitalization, first time (1x)</td>
</tr>
<tr>
<td>#5</td>
<td>15</td>
<td>Female</td>
<td>Caucasian</td>
<td>16y F (&amp; 2 half brothers in their 30’s)</td>
<td>None</td>
<td>2 weeks and 5 days</td>
<td>No</td>
<td>“Like maybe 3”</td>
<td>School chorus</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>#6</td>
<td>13</td>
<td>Male</td>
<td>African American</td>
<td>1 ½ y 7y 9y 14y F</td>
<td>14y F</td>
<td>2 weeks</td>
<td>No</td>
<td>About 12 “Except for last year every year”</td>
<td>Music lessons, self taught piano</td>
<td>Yes</td>
<td>Dec 2002 w/ a student (1x)</td>
</tr>
</tbody>
</table>
records and how he provides the beat instead of background guitar if the drummer is not there. He has the most extensive music therapy experience of all the subjects, having had “many” sessions with the music therapist on staff, Patrick, and one session with a music therapy intern. **Subject #1** indicated he preferred to primarily use the guitar in his sessions although he described playing the drum machine and singing once, each on separate occasions.

**Subject #2** is a 12 year old Caucasian male with two siblings, a nine year old brother and an eight year old sister. The eight year old sister, who also has CF, was hospitalized along with him and actively participated in all the music therapy sessions. His hospitalization was one week and four days at time of the interview and it was his first hospitalization. He had no previous music experience or music therapy but did respond that he watched music videos. **Subject #2** described playing the guitar and the drums, and being able to play the instruments together with the therapist and his sister during his music therapy sessions.

**Subject #3** is a 13 year old African American female with five siblings, sisters’ ages five months, 18 years, 20 years, and 29 years, and a brother age 11 years. The 11 year old brother is her only sibling with CF. He was hospitalized with her in the same room and actively participated in all of the music therapy sessions with her. Her mother, 18 year old sister and nephew also participated in some of the sessions. Her current hospitalization was two weeks at interview time. She indicated that she had been hospitalized about nine or ten previous times. She is infected with B Cepacia. She referred to her previous music and music therapy experience as making a music video with the music therapist during a prior hospitalization. When
describing music therapy, she discussed the therapist allowing her to “play whatever [she] wanted to play”, and talked about all the instruments, drums, guitar, piano, tambourine, maracas etc. as well as her experiences singing pre-composed songs and “making songs”.

**Subject #4** is an 18 year old Caucasian female with two siblings, both female ages 16 and 19, and diagnosed with CF. Her 16 year old sister was also hospitalized at the same time, and although she was in the room during the music therapy, she did not participate in the sessions. In addition to CF she suffered from optic nerve atrophy which severely limits her vision. She is quite near sighted and reported the vision in her right eye was 20/200. Her hospitalization at the time of the interview was two weeks and four days and she reported her previous hospitalizations were “too many to count”. She is infected with B Cepacia. She has a broad musical background including piano and voice lessons, school chorus, making music with friends and a deep musical connection with her family. **Subject #4** discussed the significance of music in her relationships with her family as well as socially. She spoke proudly of her father as a musician, “a singer, he’s sung all his life, taught himself how to play guitar.” She described country music always being on the radio in her house and her family singing while her dad played guitar. Performing with her father was also an important part of her relationship with him, something they did together since she was in kindergarten. She told a story about how helpful his support is as she depicted an event involving stage fright. In the account she explained not being satisfied with her first solo performance at school, so the following year her dad played guitar for her. She expressed her feelings as she described:
“I have really bad stage fright which is really funny because most people think I’m so outgoing, but I get really nervous when I’m performing. And performing with my dad there made it so much better, I can’t even explain how much better it made me feel…So music to me is really like a family tie…”

She discussed many of the positive experiences associated with her involvement in school chorus as well as difficulties related to missing practices and performances due to illness and hospitalizations. She talked about having many friends who are musicians and the importance of being able to create music with them. She participated in music therapy one other time during her most recent hospitalization. She reported her music therapy experience included various forms of improvisation, learning to play the harmonica, “experimenting with some drums” and “regular vocal stuff”.

**Subject #5** is a 15 year old Caucasian female with three siblings, one 16 year old sister and two half brothers in their 30’s. None of them have CF. She was hospitalized two weeks and five days at the time of the interview and had approximately three previous hospitalizations. Her previous music experience included school chorus but no music therapy experience. Her mother, father, and sister were at some of the sessions but did not participate. When describing her sessions, she talked about playing the guitar, piano, keyboard, the electronic drum set and also creating music using the computer.

**Subject #6** is a 13 year old African American male with five siblings ages one and a half, seven, nine, nine, (he explained that the nine year olds are two months apart in age), and 14 years. The 14 year old female (only one whose gender was
known) is the only sibling with CF. **Subject #6** was hospitalized for two weeks at the time of the interview and had approximately 12 previous hospitalizations, as he recalled being hospitalized every year except the previous one. His father and grandmother participated in some of his sessions as his “audience”. His previous music experience included piano lessons and self taught piano, and he had one previous music therapy experience with a music therapy intern. When describing his sessions, he discussed guitar and piano, making up his own songs and playing back and forth with the therapist.

**Major Findings**

The major findings of this research demonstrate multi-faceted, positive responses from subjects regarding their experiences with music therapy. The largest areas impacted appeared to be in the domains of cognitive and emotional responses. There were also significant effects in the area of physical responses as well as reports of music therapy affecting interpersonal relationships. (See Table 2: Subject Responses on p. 37)

All of the subjects seemed to value music therapy as a beneficial experience with most (five of the six) including the word “fun” in their initial description of what it was like to be in music therapy. Subjects commonly described playing music and instruments using additional words like “cool”, “good”, and “new”. When asked if there was anything they would have changed about music therapy, half of the subjects indicated they wouldn’t have changed anything while the other three patients expressed a desire for more music therapy. **Subject #3** said she would have liked “more time, [the therapist] should have stayed for three hours” with a similar
response from subject #6 who expressed he would like to “have it always”. Subject #5 articulated that she wished she would have also had music therapy during her previous hospitalization.
Table 2: Subject Responses

<table>
<thead>
<tr>
<th>Domains</th>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>#4</th>
<th>#5</th>
<th>#6</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>COGNITIVE RESPONSES</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-discovery</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Self-confidence</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Change in Perspective</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distraction</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extra Musical Associations</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td><strong>EMOTIONAL RESPONSES</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Self-expression</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anticipation/Reduction of Isolation</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peak Experience</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PHYSICAL RESPONSES</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Exercising</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Energy</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Reduction of Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td><strong>INTERPERSONAL EXPERIENCES</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapeutic Relationship</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationships with Family Members</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Interaction with Others</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal Associations</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: X indicates affirmative response
Cognitive Responses

Self-discovery. Subjects demonstrated awareness of value in their accomplishments through self-discovery, as was evidenced by statements regarding new experiences. Several subjects (#1, 4, 5, 6) described a new experience as beneficial. Subject #1 discovered he possessed “new talent” playing guitar that he “was good at”. Subject #4 described the new experience of improvisation as an encouraging one where she had the opportunity to express herself creatively. She explained, “that’s something I had never done before so it’s a challenge for me because we always try to do something kind of new. So it’s a challenge to try and open up and be creative and I like having that sort of challenge.” Subjects #5 and #6 expressed pleasure in trying and learning new things.

Self-confidence. A sense of freedom and comfort in their ability to express themselves was reflected in the subjects’ statements about having the opportunity to make decisions regarding the types of musical experiences they participated in. This display of confidence was especially evident in the way they indicated they would describe music therapy to a friend, with responses such as subject #1 “sweet, they should do it, awesome”; subject #2 “you could pick an instrument and just play it”; subject #3 “nice, play whatever you want to play”; subject #4 “whatever music thing you like to do”; subject #5 “pick which instrument you want to play and you can play it”; and subject #6 “they can do what they like, guitar kind of difficult, piano is decent”. Subject #4 provided the following excellent example of how she experienced an improvement in her self-confidence.
“One thing I think I always kind of do is say ‘oh yeah a lot of my friends are musicians’ but always kind of thinking of myself as something separate than that but not necessarily a musician on their level. And I think that some of the stuff we did like the music improv… made me realize I could be on their level. Because I have a couple friends who do such great music improv, like you just sit there and wonder where the book is that they’re playing from because it’s just phenomenal. And you know doing that everybody would always be like ‘we need a singer, we need a singer’. I’d be shrinking down in my seat, not wanting to volunteer my services and everybody would be like ‘******’s’ a singer. And I’d be like ‘What???’ So maybe next time [I’d be] a little less hesitant to participate than before. Cuz they’re my friends and they’re the people you care about their opinion the most. So this kind of gave me a little more confidence. So maybe next time I’ll get up and start making up words to their music cuz I’ve done it with Patrick so maybe now I can do it with the people who I actually know a little better.”

Subject #5’s confidence was evident as she recounted her experience creating music on the computer stating “that was cool…wow, I made that”.

Change in perspective. Many of the subjects exhibited awareness in their ability to think or feel differently about themselves. When asked “did you feel differently about your future during the music”, several of the subjects responses indicated a new found perspective with regards to their musical capabilities. Subject #1 explained, “I think I found something, something good to play, I think I found a good musical instrument to play”. He described previous difficulty with the trumpet because of his lungs but feeling comfortable with the guitar because he did not need to use his lungs “…unless I become a rock star and have to move around a lot”. These thoughts seemed to further reinforce his confidence in his newly discovered talents. Subject #3 expressed her thoughts amidst some giggling and singing, saying “I thought I could be on American Idol singing”. Her interactions indicated an appropriate amount of humor and realism. Subject #4 “definitely”
wanted music to be a part of her future, “not to be famous but for my own enjoyment and to socialize.” **Subject #5** discussed the possibility of playing an instrument such as guitar in school the following year. She expressed realization of her abilities as she explained “I never thought I would play the guitar then Patrick came and I did it”. Later, she reiterated “I never thought I would know how to do that, play the guitar that good…strum the keys and stuff”.

Towards the end of the interview, when asked if there was anything else the interviewer should know about her experience with music therapy **subject #3** displayed excellent awareness, responding “it makes you feel real good about yourself”. **Subject #4** also demonstrated remarkable insight as she illustrated the challenging new experience of improvisation and then depicted the subsequent verbal processing.

“There’s another thing I really liked. That we weren’t just like okay play an instrument, sing a song and move on to the next thing. We always talked about what we had done, which I think is a really important part of it because that’s how you kind of figure out what it’s really doing for you.”

**Subject #5** revealed feeling differently as a result of the music therapy, but it was not something she could put into words.

**Distractions.** Several of the subjects’ discussions indicated that the music therapy helped them to clear their heads or focus their thoughts elsewhere to distract them from their hospitalization. Although **Subject #1** “still [thought] about being in the same place”, he described an experience where “it was just zoom, where it was just the guitar and that was it. So, and listening to the other guitar, you get the beats together and you just, ahhh, just get sucked in”. This illustrated the power music had
for him as he was able to concentrate on the music and allow this release. He depicted one session where several cleaning people were in the room and he and the therapist were in the corner and he “didn’t even notice they were there,” indicating his focus on the music therapy experience. **Subject #2** said “I just thought about playing, I wasn’t thinking about anything” revealing his thoughts about concentrating on the music to the exclusion of anything else that may have been on his mind. **Subject #4** appeared to have specific ideas regarding the use of distraction techniques during her sessions as she explained “a lot of times when I’m doing this sort of music my goal is to clear my head and not think of too much stuff in my daily life like any stresses I’m dealing with or anything like that…” She further detailed,

“A lot of times when I’m either listening to music or sometimes when I’m playing music I close my eyes to make sure that I can really concentrate, to not be distracted by anything else. So sometimes it does make me feel like I could kind of not be here, just be somewhere else.”

**Subject #5’s** family members were present during the sessions but since she was focused on the music she expressed “it wasn’t even like they were there”.

**Extra musical associations.** Besides clearing their minds, two-thirds of the subjects discussed associations related to the music. One of the most common themes appeared to be centered on movie music and videos. These references occurred among **subjects #1, 3, 4, and 6.** **Subject #1** provided a vivid account of an improvisation while he described one of his favorite things about music therapy.

“I started playing this one tune, then [the music therapist] started getting into another tune. [The beginning of the movie ‘Dawn of the Dead’] has a solo and it’s just like that. He’s walking through the city with no one around, nothing, like he’s just walking through and walking through and walking through and then all of a sudden like you
just hear this music go on. It’s just down, down music with this really high pitched guitar piece like just going back and forth with different beats and stuff so. And when I started doing that it just brought [that] to my head…yeah it was really cool.”

Subject #6 explained that all of the parts of a song he produced with the therapist sounded like the end of a movie. Subject #3 pictured herself singing and dancing in a video when the therapist “was making salsa music, ‘cha cha cha’.” Subject #4 described one of her imagery experiences stating that “depending on the different types of music, it reminds me of … the theme music from movies, you know how they always have music when there’s no talking or [when] they have backgrounds or landscapes or something like that”.

Subjects #3 and #4 depicted other imagery experiences that correlated to the type of music. Subject #3 described feelings and images involving the desert, snakes, dancing, singing, church and school as she related each reference to a particular song such as “Maria”, “Lean on Me”, and “The Greatest Love of All”. Subject #4 explained that “different kinds of music reminds me of different kinds of images, usually it’s less of real thinking and more of just kind of seeing things in my mind”. She discussed how she often closed her eyes and relaxed during imagery experiences and indicated, “the more I can see [in my mind] when I’m listening to the music the more I can let myself go, see where the music ends up”. When questioned about specific images she expressed seeing lots of flowers, gardens and related images.
Emotional Responses

Mood. There was a general theme for almost all subjects related to their emotional state. Through the music therapy they expressed an ability to transform negative feelings to positive using such common descriptors as mad, down, and happy. Subject #1 offered this spontaneous response, “my mood like changed…you sort of get down just being in your room all day so when somebody comes in, just from somebody coming in, just gets you a little happy. So yeah but the music helped it out just a little bit”. Subject #1 also explained that music therapy “really helps you get through the whole thing…if you’re angry that day then you’re fine after doing it, it does help” while subject #2 suggested “if I was down I might have been happy afterwards”. Subject #3 revealed “at first I was mad… but then when Patrick came I started dancing and I got happy”. Subject #4 elaborated on her experience,

“[Hospitalization] can be very frustrating, exhausting, it can be upsetting at times. Music therapy is a way for me to push all that aside and you know get back to the positive feelings of everything is going to be okay and you know there’s stuff outside the hospital and it’s not going to last forever being in here.”

Subject #5 expressed feelings of excitement about music therapy and subject #6 responded that he was happy during the sessions but speculated that his mood probably would have changed if he had been mad.

Self-expression. Through subjects’ accounts involving experiences such as improvisation, creativity, and composition they were able to describe how music therapy provided a unique way for them to express themselves. When discussing the guitar, subject #1 said “there was no other instrument, I didn’t want to play any other instrument”. Another time he explained,
“I’m more like a beat type person instead of doing any actual type of like note, songs and stuff, I can’t do that, so when Patrick did the notes and songs and stuff on the guitar it helped me out a little bit with the beat and I never use like any notes or anything so it was all just more like just myself, and my own beats and stuff.”

For **Subject #3**, dancing appeared to be an important part of her self-expression. She danced around during the interview and responded to a question about her mood with “I just wanted to get up and” she began to sing “dance to the beat of the music, dance no one can hold me back”. **Subject #4** described many instances where she was able to express herself through vocal and instrumental improvisation. She explained “[music therapy] is not something that has rules or certain ways of doing things and it can be different for everyone which is another thing I really like about it”.

**Subject #5** indicated particular excitement about using the computer to create her own beats, explaining “that was really cool too, I liked doing that”. **Subject #6** described composing music with the therapist and indicated his happiness during the session was a result of playing music.

*Anticipation/reduction of isolation.* One of the most difficult issues of hospitalization described by the subjects was isolation. Many subjects depicted anticipating their music therapy sessions as a way to decrease the loneliness brought on by long hospital stays spent primarily in one room. **Subject #1** illustrated, “Good, really good, yeah [music therapy] just helped out a lot with I don’t know, just the day”. He further explained “Just knowing that somebody was gonna come and I was going to play something that I liked helped me out with like the morning, it just helped me out.” **Subject #3** described the therapist as one of the reasons she was not lonely during her hospitalization. Several times during the interview she eagerly
asked about the next time she would see him. **Subject #4** emphasized, “kid’s with CF, we’re not allowed to leave our rooms”. She depicted a type of boredom that could not be alleviated by watching television or reading a book and described anticipating music therapy as she said, “Coming in the hospital’s not all that cool but knowing that there’s [music therapy] to do kind of lifts my spirits a little. It gives me something to look forward to”. **Subject #5** expressed how she was “looking forward to like playing something, music, doing something different”. She also indicated she was less bored during the music therapy, emphatically stating, “There’s nothing to do in here. I’m stuck in here.”

**Peak experiences.** **Subject #1** appeared to have a peak experience as a result of his ability to successfully use methods of distraction. He offered this account when asked how his body responded to music therapy.

“I just sort of went with the beat, and everything sort of went together. It was pretty cool the way everything just blended in and like after awhile you just get into a trance somehow. You don’t see any notes, you just know to play that and play that… sort of got into this little trance here.”

When questioned about noticing the time during this experience he responded “no, I wasn’t even paying attention to the time of day, or anything, just got into it, it’s just like a trance, just conflixed on that guitar. Just sunk into me like.” **Subject #4** discussed how music therapy “puts her in a better mood” as she described the following peak experience,

“And [music therapy] makes me think about things a little more, just challenging me to do something new is always a little scary. But you know when you’re able to do it, your own satisfaction, it really gives you a feeling of accomplishment. So I felt a lot of that too.”
Physical Responses

Relaxation. When questioned if the music helped them relax, all of the subjects answered “yes”. Several of the subjects then also offered clarifying statements such as subject #1 “got me a little excited a few times, I really got into it”, subject #2 “a little bit, but if I messed up I would get frustrated”, subject #3 “I was like dancing” and subject #6 “learning new things, afterwards, feeling good”. Numerous times throughout her interview, subject #4 initiated discussion on the importance of using music to help her relax. When asked to describe what it was like to be in music therapy her initial spontaneous response was, “I really enjoy it because music is very relaxing to me, it helps me get out frustration, anger any kind of negative emotions and get back to the happy place…” She also talked about feelings of relaxation when discussing her physical responses, imagery experiences and emotions.

Exercising. All subjects questioned about exercising their muscles gave affirmative responses, and three (#2, 5, 6) of them volunteered that they specifically exercised their hands, arms or fingers. Subject #3 centered many of her responses around dancing. She often demonstrated her answers both physically and verbally as she was quite active and enthusiastic, dancing and singing throughout her interview. She indicated that she exercised her muscles during music therapy, “cuz I was dancing”. Later in a spontaneous response she recalled, “as soon as I heard the music I just wanted to start dancing.”

Energy. Five of the six subjects felt the music gave them more or a little more energy, while subject #6 reported he had the same amount of energy. Although
subject #1 responded a “little more” to exact questioning, several other times he described experiences that specifically focused on his feeling “energized”. His descriptions included words like “excited”, “energetic”, “entertaining”, and “I got into it”. Subject #2 also answered he had “a little bit more energy” then when asked to describe in more detail how that felt, he explained, “like I thought I wouldn’t be tired anymore”. Minutes later he volunteered, “it felt like I got a little bit more power”. Subject #3’s increased energy was apparent during the interview through her descriptions and reenactments of the dancing from her sessions. When asked if she noticed any changes in her body during the music, subject #4 gave this detailed description,

“…I think it gives me more energy because it’s something I enjoy, get out all the negative energy. It makes me feel like after the music session is over, like, what can I do now? I don’t want to just hang around and do nothing. It kind of gives me a lot of energy. It puts me in a good mood and revamps me to do other stuff.”

Breathing. Three subjects (#3, 4, 5, all of the female subjects) indicated a change in their breathing. When asked if she noticed a change in her breathing during the music therapy, subject #3 demonstrated deep, heavy breathing. She elaborated on her experience, explaining “I was like breathing a little more faster…it’s normal to breathe hard when you’re dancing and stuff…it loosened up the mucus.” Subjects #4 and #5 both expressed how playing the harmonica positively impacted their breathing. Subject #4 described her experiences with the harmonica as “exciting” and “cool”. In a spontaneous response about her body, subject #4 explained, “Definitely when we did any kind of vocal stuff, it helped my breathing which is another reason I really like singing. I feel it makes my lungs healthier.” Later when
the interviewer asked her to talk more about her breathing and singing she gave this poignant example,

“Definitely having to be able to control your breathing with singing helps a lot. It helps me do my pulmonary function tests which are the big tests that they base how we’re doing. They base a lot on that test and one music therapy session I had was right before the test that I had done the one day and we did a lot of singing that day. My test turned out really well and it was really a lot easier for me to do because the singing was kind of like a warm up, you know, for the breathing test. So it just makes things a little easier. It makes breathing a little easier, I guess, a little more comfortable. So it’s really great for that”.

Subject #5 reported she exercised her lungs while playing the harmonica, further describing her experience as “fascinating, kind of hard… I just blew into it, but it was cool.”

Reduction of pain. Only one subject, subject #2 indicated having some pain while in the hospital but responded he had “no pain” during his music therapy sessions.

Interpersonal Experiences

 Therapeutic relationship. Many of the subjects expressed the value of their relationship with the music therapist. Subjects referred to Patrick by name, spoke openly and positively about him, talked of looking forward to their sessions and expressed a desire to spend more time in music therapy sessions. They discussed their ability to relate to him both musically and verbally as an important part of their experiences. Subject #1 had worked with Patrick “many times” before and stated “I didn’t know I could play the guitar until Patrick got me on to it”. He explained how, “my favorite thing would have to be when we really started getting a good beat” and also described how “when Patrick did the notes and songs and stuff on the guitar it
helped me out a little bit with the beat”. Subject #3 expressed, “I wish he could come back again and play the music” and she began her account of how she would describe music therapy to a friend with how nice Patrick is. Subject #4 indicated the “music therapist is really cool…Patrick’s great…we really were able to talk about a lot of things and I guess do a lot of things on the same level so we kind of connected so that was really cool.” She explained, “the more sessions we had, the better I got to know Patrick, then the more comfortable I was with whatever we were doing”. She described the support she received during her sessions,

“The whole point of the music therapist is to kind of let you do your own thing, encourage you and maybe help you out if you’re kind of stuck. You know what I mean. And having that makes it like a different music experience than if you were just singing along to the radio or learning a new song in a choral group or even when I’m singing along with my dad’s guitar or playing piano finger exercises. Having that other person in that kind of role makes it a totally different kind of experience than just normal everyday music stuff. Which I think is a good thing because it kind of makes you loosen up and think of things that you might not think of doing and do things that you might not try on your own which I think is usually a good thing.”

Subject #4 emphasized the importance of her interaction with the therapist as she said, “playing with another person was really awesome. I don’t get to do that necessarily that often because usually it’s me and an accompaniment.” She illustrated her experience of,

“just having someone to talk to even when we weren’t talking. If we were both playing the keyboard improv, just knowing someone else is there and you’re working together without verbally communicating, which I think is really cool to be able to do that.”

Subject #5 stated feeling excited when the music therapist arrived for her sessions. She gave this description when asked if she was able to talk about her feelings during music therapy,
“Like, how can I say this, like I felt like I couldn’t do it as good as he was doing it, weird cuz he was really good. Everything he played he was really good at. Like I tried and I was like, oh my God it doesn’t sound like that, get frustrated”.

She appeared comfortable relating to the therapist as she expressed she was able to discuss her frustration and indicated “it was fine” when she was able to talk to him about it.

Relationships with family members. Several subjects described valuable experiences with family members during their music therapy sessions. The hospitalized siblings of subjects #2 and #3 actively participated in the music therapy sessions with their brother and sister (respectively). Subject #2 indicated he got along well with his sister and her involvement helped them, “[sound] like a band” during his sessions. Subject #3 shared a hospital room with her brother and their bond appeared strong as they interacted favorably and joked around during the interview. She reported her brother “was fun when we started singing and dancing” during the music therapy. She also described having fun with her mother and sister in a session because she was able to make her little nephew dance. Subject #6 seemed to like to perform for his family members. He indicated they were the “audience” during his sessions and explained how interactions with his grandma did not change during the sessions because “I always call home and play piano while she’s on the phone”.

Interaction with others. Two of the subjects reported differing experiences with staff members’ involvement in their sessions. Subject #1 described the impact a nurse had on one of his sessions,
“Like one nurse sat in through a session and I was sort of messing up that day. As soon as she left that was it, I was back, I don’t know, just an audience, makes me like a little nervous. Like if they’re playing with me then that’s normal, but an audience makes me mess up a little. I’m still not used to that yet but we’re working on it”.

Subject #4 portrayed an experience where after a doctor examined her and her sister he picked up Patrick’s guitar and they had a “jam session” that was “really funny and really cool”. These situations may offer insight into the importance of personal involvement in patient care as each subject emphasized the significance of interaction.

Interpersonal associations. Three subjects (#1, 4, 5) described experiences where they had associations related to family or friends during the music therapy. Subject #1 was reminded of his uncle during the music because he also plays guitar. In talking about his uncle he said, “maybe I could get together with him one day and play, that’s what really made me think of him.” Subject #4 said that she definitely thought about her father because she “kind of learned music from him”. Subject #5 thought about forming her own band during the music therapy sessions. She explained this as somewhat of a fantasy where she would form the band with friends and humorously described how it would “probably sound really bad” and they would “play a mixture of stuff” due to their different tastes in music.
CHAPTER 5: DISCUSSION

Overview

The results of this study provide a comprehensive representation of how these six patients experienced music therapy as formulated from their own descriptions gathered during the interviews. The most prevalent benefits appeared to be in the cognitive and emotional response areas with subjects reporting an improvement in coping styles, self-discovery, self-confidence, and a change in perspective, as well as decreased isolation and improved mood. Many subjects reported imagery experiences and the benefits of using music therapy to clear their heads or for distraction. A variety of physical benefits were reported by all of the subjects. Several subjects also reported positive interactions with the therapist and others during music therapy. All of these responses support the use of music therapy for hospitalized adolescents with CF. These findings also suggest that music therapy has benefits that are encountered and recognized by these patients.

There appear to be no articles available examining the music therapy experiences of adolescents with CF, based on self-reports. The purpose of this study was to explore the impact of music therapy on hospitalized adolescents with CF from their own perspective. The responses from the interviews support findings regarding psychological issues of CF, hospitalization and the effects of music therapy described in the literature review section of this paper. It was important to investigate this phenomenon, as physical and psychological issues appear common for these patients (Bluebond-Langer et al., 2001). Since these concerns can be addressed by using music therapy to promote positive aspects of emotional and physical well-being,
findings from this study may be beneficial for further clinical application and research development.

Description of Major Findings

Although no exact research exists for which to make a comparison, this study provided results that support previous applicable research. Like similar studies with adults, by Goloff (1981) and Goodman (2000) where patients described positive experiences, subjects in this study also described their experiences as “fun”, “cool”, and “exciting”. Cognitive responses seemed especially prevalent, as many subjects offered detailed accounts of instances where these changes in cognition occurred during their sessions. Subjects communicated the value of their experiences as they depicted their change in perspective, expressed self-confidence, described with affirmation occasions to create music, and explained their ability to use music therapy to facilitate imagery, distraction and positive associations to aid in their coping skills. These reports confirm findings detailed in the literature review that music therapy is often used to promote greater self-esteem and improve coping skills.

When questioned about the future, subjects often gave answers which focused on their musical experiences and not their illness. This process of ‘adaptive denial’ appears to be a coping mechanism frequently seen in patients and families of patients with CF (Bluebond-Langer et al., 2001). Individuals were able to concentrate on positive experiences of self-discovery attained during their sessions and relate those to their future. Subjects sometimes recognized the significance of something meaningful occurring even if they were unsure exactly what it was or how to fully articulate it. For example, when subject #5 was questioned if she thought about
herself in a different way during the music, she initially was slightly hesitant and then laughingly replied, “honestly yes, but you’re going to ask me how to explain it and I’m not going to know how”.

Outcome data establishes that all subjects indicated beneficial results in the way their mood responded to music therapy. Since both hospitalization and adolescence are difficult for these patients, this finding appears to be significant. Several of the subjects discussed the difficulties of hospitalization, including isolation, fatigue, and dysphoric mood. Subjects expressed an ability to transform negative feelings to positive using such common descriptors as “mad”, “down”, and “happy”. Most seemed willing to openly discuss their feelings and expressed valuable opportunities for self-expression provided during the music therapy sessions. Many of the subjects reported anticipating the music therapy sessions as a way to reduce isolation and decrease boredom. Subjects’ reports substantiate findings in the literature indicating that music therapy during pediatric hospitalization provides opportunities to improve self-expression, decrease isolation, and promote feelings of normalization (Brodsky, 1989; Colwell et al., 2005; Lathom-Radocy, 2002; Robb, 2000).

As stated earlier, Bluebond-Langer et al. (2001) characterize the ongoing struggle of feeling different from their peers as one of the major psychological issues school-age children and adolescents with CF face. Throughout the interview process several subjects expressed the potential to view themselves as normal as a result of their music therapy experience. Subjects appeared to convey these feelings as they
answered various questions with responses containing words/phrases such as “normal” and “the same as anyone else”.

Prior studies determined positive experiences with exercise, deep breathing and increased range of motion as some of the benefits of music therapy (Dun 1995, Griggs-Drane 1999, Rudenberg & Royka 1989). All subjects in this study expressed opportunities for relaxation and exercise, while five of the six reported increased energy and portrayed feeling excited, more powerful, and re-energized. Subjects who reported an impact on their breathing described the experience as positive and beneficial using such words as “fascinating”, “exciting”, and “cool”. They discussed issues specifically related to CF as they illustrated how music therapy experiences made breathing easier and more comfortable, helped to loosen up mucus, and provided an opportunity to exercise their lungs. One subject also described how she felt she did well on a pulmonary function test as she explained feeling warmed up from singing during a music therapy experience. She depicted her sense of ease in breathing which carried over during the test that immediately followed her music therapy session. Although pain did not appear to be a significant issue for these patients, the one subject who reported pain during his hospitalization indicated experiencing no pain during music therapy.

The importance of the therapeutic relationship was described by several of the subjects, substantiating the research of Edwards (1999), Jacobowitz (1992) and Robb (2000). These results, including observations made by the interviewer, indicated the subjects had a good rapport with the therapist. They spoke about him respectfully as well as humorously, expressed excitement and anticipation for their
sessions and often desired to increase their music therapy time. Many also articulated the value of the support and encouragement he provided, reinforcing evidence of the strong connection these patients developed with their therapist. As previously stated, the music therapist plays a unique and supportive role in helping children cope with their hospitalization. The value of time and personal contact can never be underestimated. Development of the therapeutic relationship allows the music therapy experience to strengthen the connection between patient and therapist providing an avenue to foster optimal health in the client.

Subjects reported favorable results of enhanced relationships as family members participated in sessions and a few unique interactions with staff were recalled. Several subjects discussed thoughts and memories of friends and family members that occurred during music therapy experiences. In addition, several reflected on the value of family and social relationships related to past musical experiences.

Only a few gender issues were noticed. All of the female subjects reported positive changes in their breathing while no changes were reported by any of the male subjects. While four subjects discussed movie references during the interview, subjects #1 and #6, both male, described their own music compositions as sounding like movie music, whereas subjects #3 and #4, both female, discussed movie music references when describing imagery experiences.

Overall age did not appear to be a major factor, though age differences may have offered some unique perspectives. For example, during the description of the imagery experiences, female subjects #3 and #4 had some similarities in their
descriptions. However, the more concrete examples from 13 year old subject #3 compared to the more abstract examples of 18 year old subject #4 provide a distinctive glimpse into their individual perceptions.

Race did not seem to be an issue; though it is of particular interest to note the high ratio of African American subjects in the study (2/6) in comparison to general population of patients with CF. The frequency of CF in live births is one in 2,500 for Caucasians, and one in 17,000 for African Americans (“Cystic Fibrosis Foundation”, 2005). The researcher was unable to account for this anomaly.

The open-ended personal interview style was chosen to allow subjects to respond freely and spontaneously using their own words and to provide an opportunity for them to express their ideas (Oppenheim 1992). Confirmation of the value of using this technique was clearly evident. The conversational format allowed various topics to be openly discussed throughout the interview, even if not initially expressed in response to a specific question. For example, when questioned about previous musical experience subject #1 only talked about playing trumpet, however over the course of the interview, he opened up about his experience playing guitar with friends in a band. This phenomenon seemed particularly evident in the area of emotional responses where subjects’ descriptions of their affective changes were interspersed throughout the interview.

The in-depth interview technique seemed especially effective for this age group as the open-ended style appeared to allow subjects to willingly share what they really meant or felt. Throughout the in-depth interview process, the descriptions from the subjects sometimes varied from their initial answers, and clarity was often added
through their own words. For example subject #1 would often begin a response with “nope” and then as he talked his answer would change to an affirmative response, as he offered a more detailed explanation. Several other subjects displayed similar tendencies in their responses. For instance, when questioned if the music helped them relax all of the subjects originally answered “yes”. Some of them then initiated clarifying statements that conflicted with their initial answers such as subject #1 “felt excited, really got into it”, subject #2 “a little bit, but if I messed up I would get frustrated”, and subject #3 “I was like dancing”. In some cases this may have indicated their individual interpretation, perception or definition of the word “relax” and their associated feelings. It is also possible subjects had difficulty putting specific concepts into words or were unsure how to bring up certain issues. This was evident in the case of subject #2 where his response may have indicated potential feelings of anxiety related to the music.

Clinical Applications

Based on the outcome of this study, it can be concluded that music therapy had multiple observable benefits for these patients. The similarities of the results found in this study with previous research on music therapy with hospitalized children and adolescents indicate that these findings are not unique to this study. These comparisons allow the results of this study to be applied in similar music therapy situations. By obtaining extensive information directly from the child about his/her music therapy experience therapists can develop a better understanding about the many ways an individual experiences music therapy. The in-depth information gleaned from the interviews in this study will help therapists when they work with
these patients in the future to develop practical music therapy goals and treatment. Since other chronically ill adolescents (including those with cancer, asthma, diabetes, cardiac issues, and kidney disease) face comparable issues such as frequent hospitalizations and significant time in isolation, results may generalize to include these individuals.

As previously stated, respiratory problems are a significant issue for this population (Bluebond-Langer et al., 2001). Results of this study support research by Ellen Griggs-Drane (1999) that music therapy produced “emotional, physiological and physical benefits” (p.130) for patients with pulmonary illnesses. Half of the subjects reported that music therapy positively impacted their breathing. Per these accounts, clinical applications may focus on techniques to ease breathing, clear mucus, exercise lungs, and improve breath support and control.

Half (3/6) of the subjects had siblings hospitalized at the same time. Of those, two subjects (#2, #3) had siblings who actively participated in their music therapy sessions. Reports of positive and increased interactions with family members confirm the potential benefits of family therapy in the hospital environment.

The value of the creative arts therapies was apparent from the information gleaned during the interviews. Subject #3 discussed receiving art therapy and appeared to be an excellent candidate for dance/movement therapy. She creatively expressed herself using dance and movement throughout the interview and portrayed many instances when she danced during her music therapy sessions. Subject #5 also discussed receiving art therapy, and evidence of her treatment was prominently displayed throughout her room.
Limitations of the Study

In this research, using distinctive music therapy techniques tailored to each individual was important; however the implementation of a specific music therapy protocol may have produced a different outcome. A set protocol might have allowed for more generalization of data across the board but also may have changed the way subjects perceived the sessions if they were not designed to specifically meet their unique needs. Prior experience with music therapy may have impacted the results, as subjects may have previously developed a relationship with the therapist and worked on therapeutic goals. Further research may limit these variables.

The researcher as the interviewer created potential for bias in the study. The researcher had some definitive ideas as to the desired possible outcomes of the study. These ideas may have presented themselves consciously or unconsciously in the form of leading subjects to particular answers during the interview process. Also, as a result of personally conducting the interviews and the significant amount of time spent analyzing the data, the researcher felt a unique connection to the subjects. In any study it is impossible to completely exclude any bias, however in the most ideal situation, different individuals would function as the researcher, the interviewer, and the music therapist.

There appeared to be a variation in interviewing style that came with experience. Some of the questions became more probative as the interviewer felt more comfortable with the style. This tendency may have also occurred as a result of the interviewer being the researcher. Initial interviews were transcribed as they were completed, and unintentionally, preliminary interpretation of the data began to occur.
Through critical self-analysis of the interviews, the interview process became clearer and places where prompting seemed appropriate and beneficial were revealed. It is this researcher’s opinion that the progression helped the researcher become a better interviewer. This may have affected the results from interviews that occurred later in the study.

A suggested change in the interview style for future studies would be to further develop ways to elicit information before moving on to researcher generated topics. One potential technique uses phrases such as “tell me more”, “Can you explain what that was like?” or “Describe what you mean by….?” This researcher determined it would be valuable to use this method at the beginning of the interview as well as throughout the entire interview process, allowing for the collection of more detailed information. This practice may also foster better participation as subjects’ responses are validated and they perceive the interviewer to be an active listener.

Some environmental and health factors may have affected the interview process, such as the time of day or the patient’s emotional or physical state. **Subject #2** had been sleeping prior to his interview and immediately went back to sleep at the conclusion of his interview. A video game seemed a source of distraction for part of **subject #6’s** interview until the interviewer intervened. **Subject #4** had multiple interruptions during her interview, and health issues caused rescheduling of **subject #5’s** interview a few times. **Subjects #4 and #5** (female) seemed fully invested in the interview despite interruptions and rescheduling, however **subjects #2 and #6** (male) both gave minimal responses. If interviewed at a different time, responses from **subjects #2 and #6** may have been lengthier. It is difficult to ascertain whether the
quality of the answers was related to the subjects’ emotional or physical state, gender, age, subjects’ personality or any number of other variables.

Role of the Researcher

The researcher as the interviewer allowed a unique occasion for the researcher to refine her skills as an interviewer. The methodology implemented during the data analysis provided an opportunity for significant review of the interview process and content. If the study were to be repeated using the same interviewer, the outcome might be quite different as a result of the considerable experience acquired during this research.

As a music therapist, it is neither possible nor desirable to step entirely out of that role when one becomes the researcher or the interviewer. Without question the interviewer responded to the subjects with the understanding and abilities of a music therapist. The researcher felt it was important to set up the interview to put the subjects at ease so initial questions were structured to get to know the subjects and the interviewer took ample time greeting the subjects. Most of the subjects seemed comfortable with the interviewer as they often revealed their distinct personalities and humorous dispositions. In subject #3’s unique situation the interviewer needed to stay for almost an hour after the conclusion of the interview, waiting to speak with the parent to finalize paperwork. This allowed more time with the subject, where, at her request, she listened with apparent delight to the entire tape of the interview while the interviewer played games with her brother. As a result of careful observation and increased interaction time, the researcher acquired a distinctive perspective on this particular subject. During subject #6’s interview, he formulated a conclusion that all
of the parts of a song he produced with the therapist sounded like the end of a movie. This experience was similar to the type of verbal processing that normally occurs in a music therapy session.

The researcher had a personal background with CF including a childhood friend and relatives with the disease, as well as clinical experience treating patients with CF, which may have affected the study. Admittedly, questions surrounding preconceived notions about patients with CF were one of the reasons for choice of research topic. An individual with CF eloquently summarizes a perception about personality the researcher had speculated about.

“The saving grace, I have noticed, for all of us with CF is our personality…I don’t believe I’ve ever met one who isn’t funny and out for a good chat or a laugh. I think the same can be said for a lot of people with illnesses; they have more to worry about than the ‘norm’, so they see things from a different perspective and, given the chance, live it to the full” (Bluebond-Langer et al., 2001, p. 35).

Implications for Future Research

Replication of this study may be warranted as limited information appears available in the form of self-reports from children with CF or other chronically ill young patients. Research indicates there is a great deal of valuable information to be gained from the perspective of the young patient, which is an area in need of study (Bluebond-Langer et al. 2001; Maranto 1996). A direct duplication may examine consistency of results found in this study. Replication with non-hospitalized individuals with CF could provide valuable information and permit comparison with this study to determine any disparities related to the needs of the individuals, treatment issues, goals, etc. Other considerations in replication of this study may
include focus on issues including chronic illness, isolation, quality of life, or the therapeutic relationship. Individuals with kidney disease, cardiac issues, sickle cell anemia, diabetes, chronic obstructive pulmonary disease (COPD), severe burns or cancer may be potential subjects for future studies as they face concerns similar to the patient with CF.

Additional research could include comparison of subject’s perception with the perception of the therapist to help determine efficacy of treatment. One might consider evaluating tapes of the therapy sessions as well as the interviews to broaden the scope of the study. This could include video tape for data collection and comparison purposes since video could provide valuable physical information not evident in the audio format.

As previously stated, individuals with CF, especially adolescents, experience some difficulty with adherence to self-care regimes. In reports given by patients with CF and their family members, there is often a favorable discrepancy between quality of life and their actual health status as the severity of their illness is often worse than perceived (Staab et al., 1998). Results of this study demonstrated evidence of subjects’ improved coping skills, especially in the emotional and cognitive response areas. Goodill (2005) discussed “coping style and self-efficacy… [as] factors [which] have been linked to adherence” (p. 77). Future research may comprise examining the effects of music therapy on individuals’ coping styles and adherence to self care.

Future research may include exploring the impact of music therapy on the respiratory function of patients with CF using self-reports and/or pulmonary function as the outcome measure. Research may examine patients’ ability to use singing or
playing an instrument as a tool to help them evaluate their sense of being sick and investigate their capacity to care for an instrument which may enhance self-care and infection control techniques. Since all of the female subjects reported positive changes in their breathing, while no changes were reported by any of the male subjects, future research could examine this discrepancy. Additional studies could develop new techniques for the use of music therapy in the treatment of pulmonary illnesses.

Two of the siblings who actively participated in music therapy sessions were involved in the interview process, but due to their ages, data obtained from them was excluded. Subject #2’s sister appeared excited about the possibility of being involved in the study, as she had been anticipating the arrival of the interviewer and was interviewed separately at her request. Subject #3’s brother introduced himself by joking with the interviewer trying to insist that he was 12 years old. He actively participated in his sister’s interview, generally answering questions in reference to his experience but occasionally clarifying her responses. These findings indicate the potential for research evaluating the experiences of siblings who participate in music therapy together.

The results from this study may be used as the foundation for the development of outcome research by creating quantitative studies for patients with CF and similar illnesses. One possibility may involve repeating the research on a larger scale using hospitalized children with various diagnoses and developing a survey based on those results. Future quantitative studies could also implement the Cystic Fibrosis Questionnaire(CFQ)-Child or CFQ-teen/adult as they are proven measures of health
related quality of life for individuals with CF (Avani, Modi, & Quittner, 2003; Quittner, Buu, Messer, Modi, & Watrous 2005).

Findings from this study may also be used to inform music therapists and educators how the hospitalized child with CF perceives the effects of a music therapy session so that specific treatment methods may be further developed. Through obtaining extensive information from the child about the session, the therapist can learn more detail about the many ways he/she has been affected by music therapy. This information will help the therapist, when they work with these patients in the future, to develop realistic music therapy goals and approaches. By educating the therapist on the specific needs of the patients, the patients will benefit from therapy that is most appropriate for their individual needs.
CHAPTER 6: SUMMARY AND CONCLUSIONS

The objective of this study was to examine how adolescents with CF perceived the effects of music therapy on their physical, psychological and interpersonal states during hospitalization. It is understood that hospitalization can impact these patients in various ways. These problems may include regression, anxiety, isolation, stress, depression, diminished self-esteem, and adjustment issues which may impact the course of their illness and hospitalization. Professionals in health care need to recognize the importance of addressing these psychological issues as well as meeting the physical needs of their patients.

In this study, music therapy was provided for six adolescents hospitalized with a diagnosis of CF. Each subject received three music therapy sessions and then participated in an interview. The music therapy sessions were tailored to meet his/her individual needs. The interview consisted of questions regarding the subjects’ music therapy experiences, hospitalization and some brief background information. Topics examined in the interview were introduced with broad, open-ended questions then progressed to more specific inquiries to cover areas that had not been addressed.

The results of this study provided a considerable amount of conclusive information concerning the perspectives of these patients during their music therapy experiences. Subjects all appeared to experience music therapy positively with descriptions such as “fun”, “cool”, “good”, and “new”. The most prevalent effects appeared to be in the cognitive and emotional response areas with subjects reporting an improvement in coping skills, self-discovery, self-confidence, and a change in perspective, as well as decreased isolation and improved mood. Many subjects
reported imagery experiences that provided for a change of mental focus to less stressful perspectives. Subjects also described a variety of physical benefits and valuable interpersonal experiences. These findings support the use of music therapy for hospitalized adolescents with CF and suggest that music therapy has benefits that are encountered and recognized by these patients.

The results from this study may be used to inform music therapists, educators and other health care professionals concerning the needs of hospitalized patients with cystic fibrosis. By obtaining extensive information directly from the child about his/her music therapy experience, one develops a better understanding about the many ways the individual experiences music therapy. The in-depth information gleaned from the interviews in this study will help the therapists when they work with these patients in the future to develop practical music therapy goals and treatment methods. This knowledge will also be useful to other health professionals in developing a better understanding of the benefits experienced during music therapy by the hospitalized adolescent with CF.
REFERENCES

About teen depression (n. d.). Retrieved February 25, 2006 from
http://www.about-teen-depression.com/depression-statistics.html

services. Pediatrics, 106(5).

measure of health related quality of life for children with cystic fibrosis.
from Oxford Journals Database.

and child life interventions with pediatric burn patients. In M. A. R. Froehlich
(Ed.), Music therapy with hospitalized children (pp. 87-108) Cherry Hill, NJ:
Jeffrey Books.

being, physical comfort, and exercise endurance of bone marrow transplant

of Cystic Fibrosis. London: Arnold.


isolation rooms. Music Therapy, 8(1), 17-34.


Depression research at the National Institute of Mental Health (updated 2/17/06). Retrieved February 26, 2006 from http://www.nimh.nih.gov/publicat/depresfact.cfm


APPENDIX A
Consent/Assent Forms
For the purpose of this study both forms were called consent forms. In the following examples the first form is the consent form, and the second form is the assent form.

THE CHILDREN’S HOSPITAL OF PHILADELPHIA
CONSENT FORM

May 2003


TITLE OF RESEARCH: Hospitalized children with cystic fibrosis: The perceived effects of individual music therapy sessions on their physical, psychological, and interpersonal states

SUBJECT NAME

EXPLANATORY INFORMATION
You are being asked to participate in a research study. The purpose of this study is to find out what effects music therapy has on you. You are being asked to participate in this study because you are a hospitalized child previously diagnosed with cystic fibrosis and you have been referred to music therapy by a child life specialist. Six to 12 children will participate in this study.

This research study is being conducted by Caryn Widrick in partial fulfillment of the requirements for the degree of Master of Arts at Drexel University College of Medicine.

If you agree to participate in this study, the following things will be done:

- You will be asked to participate in three 30-60 minute music therapy sessions conducted by a music therapist. Music therapy sessions will consist of some of the following activities:
  - Musical and verbal interaction with the music therapist
  - Playing musical instruments
  - Singing
  - Listening to music
  - Composing music

- You will be interviewed for 20-45 minutes. The questions will be about your experiences with music therapy and being in the hospital.
- The music therapy sessions and interview will be audio taped. All audio tapes will be destroyed within one year of the conclusion of the study.

RISKS
As in any physical activity, you may experience some fatigue during the music therapy session. There is also a chance of injury during the music therapy session, but
this is rare. As in any interview situation, you may experience some nervousness or fatigue during the interview.

**BENEFITS**

Although the musical experiences are meant to be enjoyable, you may not benefit directly from participating in this study. However, future children with cystic fibrosis may benefit from information learned in this study.

**ALTERNATIVES**

The alternative to participating is not to participate.

**CONFIDENTIALITY**

All information collected in this study will be kept strictly confidential, except as may be required by law. If any publication results from this research, you will not be identified by name. All notes and audio tapes that may identify you by name will be kept in a secure locked cabinet in the office of Paul Nolan, Director of Music Therapy Education, Room 1027, Bellet Building, Drexel University, Hahnemann Center City Campus. These notes and audio tapes will be destroyed within one year after completion of the study.

**ADDITIONAL INFORMATION**

We may need to stop your participation in the study before the end for any of the following reasons:

a. Change in your medical condition; or
b. Other reasons, including new information available to the investigator or harmful reactions experienced by others in this study.

If new information becomes known that will affect you or might change your decision to be in this study, you will be informed by the investigator.

Being in this study is voluntary. Your healthcare will not be affected in any way if you decline to be in or later withdraw from the study.

**FINANCIAL CONSIDERATIONS**

You will not be paid for your participation in this study. You will not be charged for any aspect of this study.

**QUESTIONS**

All of your questions should be answered to your satisfaction before you consent to participate in this study, but if you have any further questions about the study you may call Barbara T. Heinrich, CRNP, at (215) 590-4684. If you have any questions about the rights of research subjects you may call the Lynn Bevan in the Office of Research Regulatory Affairs at (215) 590-2830.

**INJURY COMPENSATION STATEMENT**

Neither this Hospital nor any government or other agency funding this research project will provide special services, free care or compensation for any injuries resulting from this research. Treatment for such injuries will be provided under the same financial arrangements as those under which treatment is usually provided.

If you believe that you have suffered any injury as a result of participating in this research, you may contact Barbara T. Heinrich, CRNP, at (215) 590-2830 or Lynn Bevan.
at (215) 590-2830. They can review the matter with you, identify other resources that may be available to you, and provide further information as to how to proceed.

**VOLUNTARY CONSENT**

You are free to withdraw or refuse your consent, or to discontinue your participation in this study at any time without jeopardizing your continuing care at The Children’s Hospital of Philadelphia.

I voluntarily give my consent to participate in this research study. I understand I will be given a copy of this consent form.

**SIGNATURES**

Parent/Legal Guardian_____________________________ Date_______________

Person Obtaining Consent__________________________ Date_______________
THE CHILDREN'S HOSPITAL OF PHILADELPHIA
CONSENT FORM

May 2003


TITLE OF RESEARCH: Hospitalized children with cystic fibrosis: The perceived effects of individual music therapy sessions on their physical, psychological, and interpersonal states

SUBJECT NAME__________________________________________

EXPLANATORY INFORMATION

Your child is being asked to participate in a research study. The purpose of this study is to find out what effects music therapy has on him/her. Your child is being asked to participate in this study because he/she is a hospitalized child previously diagnosed with cystic fibrosis and has been referred to music therapy by a child life specialist. Six to 12 children will participate in this study.

This research study is being conducted by Caryn Widrick in partial fulfillment of the requirements for the degree of Master of Arts at Drexel University College of Medicine.

If your child participates in this study, the following things will be done:

- Your child will be asked to participate in three 30-60 minute music therapy sessions conducted by a music therapist. Music therapy sessions will consist of some of the following activities:
  - Musical and verbal interaction with the music therapist
  - Playing musical instruments
  - Singing
  - Listening to music
  - Composing music

- Your child will be interviewed for 20-45 minutes. The questions will be about his/her experiences with music therapy and being in the hospital.

- The music therapy sessions and interview will be audio taped. All audio tapes will be destroyed within one year of the conclusion of the study.

RISKS

As in any physical activity, your child may experience some fatigue during the music therapy session. There is also a chance of injury during the music therapy session, but this is rare. As in any interview situation, your child may experience some nervousness or fatigue during the interview.
BENEFITS
Although the musical experiences are meant to be enjoyable, your child may not benefit directly from participating in this study. However, future children with cystic fibrosis may benefit from information learned in this study.

ALTERNATIVES
The alternative to participating is not to participate.

CONFIDENTIALITY
All information collected in this study will be kept strictly confidential, except as may be required by law. If any publication results from this research, your child will not be identified by name. All notes and audio tapes that may identify your child by name will be kept in a secure locked cabinet in the office of Paul Nolan, Director of Music Therapy Education, Room 1027, Belet Building, Drexel University, Hahnemann Center City Campus. These notes and audio tapes will be destroyed within one year after completion of the study.

ADDITIONAL INFORMATION
We may need to stop your child’s participation in the study before the end for any of the following reasons:

  c.  Change in your child's medical condition; or
  d.  Other reasons, including new information available to the investigator or harmful reactions experienced by others in this study.

If new information becomes known that will affect your child or might change your decision to be in this study, you will be informed by the investigator.

Being in this study is voluntary. Your child’s healthcare will not be affected in any way if you decline to allow him/her to be in or later withdraw from the study.

FINANCIAL CONSIDERATIONS
Your child will not be paid for his/her participation in this study. You will not be charged for any aspect of this study.

QUESTIONS
All of your questions should be answered to your satisfaction before you consent to participate in this study, but if you have any further questions about the study you may call Barbara T. Heinrich, CRNP, at (215) 590-4684. If you have any questions about the rights of research subjects you may call the Lynn Bevan in the Office of Research Regulatory Affairs at (215) 590-2830.

INJURY COMPENSATION STATEMENT
Neither this Hospital nor any government or other agency funding this research project will provide special services, free care or compensation for any injuries resulting from this research. Treatment for such injuries will be provided under the same financial arrangements as those under which treatment is usually provided.

If you believe that your child has suffered any injury as a result of participating in this research, you may contact Barbara T. Heinrich, CRNP, at (215) 590-2830 or Lynn Bevan at (215) 590-2830. They can review the matter with you, identify other resources that may be available to you, and provide further information as to how to proceed.
VOLUNTARY CONSENT
You are free to withdraw or refuse your consent, or to discontinue your child's participation in this study at any time without jeopardizing your child's continuing care at The Children's Hospital of Philadelphia.

I voluntarily give my consent to have my child participate in this research study. I understand I will be given a copy of this consent form.

SIGNATURES
Parent/Legal Guardian_________________________ Date_______________

Person Obtaining Consent_______________________ Date_______________

CHILD ASSENT DOCUMENTATION
I certify that the study described above has been explained to______________________ in terms he / she could understand and that were appropriate to his / her age and ability to comprehend, and that he /she freely assented to participate in this study.

Signature of Subject_____________________________ Date_______________

Person Obtaining Assent_________________________ Date_______________
Addendum to Consent Form for IRB #2002-5-2775

Protocol Title: Hospitalized Children with Cystic Fibrosis: The Perceived Effects of Individual Music Therapy Sessions on their Physical, Psychological and Interpersonal States
Principal Investigator: Barbara Heinrich

AUTHORIZATION TO SHARE PERSONAL HEALTH INFORMATION IN RESEARCH

The word "you" means both the person who takes part in the research, and the person who gives permission to be in the research. This form and the attached research consent form need to be kept together.

We are asking you to take part in the research described in the attached consent form. To do this research, we need to collect health information that identifies you. We may collect the results of tests, questionnaires and interviews. We may also collect information from your medical record. We will only collect information that is needed for the research. This information is described in the attached consent form. For you to be in this research, we need your permission to collect and share this information.

We will share your health information with people at the hospital who help with the research. We may share your information with other researchers outside of the hospital. We may also share your information with people outside of the hospital who are in charge of the research, pay for or work with us on the research. Some of these people make sure we do the research properly. The "confidentiality" section of the consent form says who these people are. Some of these people may share your health information with someone else. If they do, the same laws that the hospital must obey may not protect your information.

If you sign this form, we will collect your health information until the end of the research. We may collect some information from your medical records even after your direct participation in the research project ends. We will keep all the information forever, in case we need to look at it again. We will protect the information and keep it confidential.

Your information may also be useful for other studies. We can only use your information again if a special committee in the hospital gives us permission. This committee may ask us to talk to you again before doing the research. But the committee may also let us do the research without talking to you again if we keep your health information private.

If you sign this form, you are giving us permission to collect, use and share your health information. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. You need to sign this form and the attached consent form if you want to be in the research study. We cannot do the research if we cannot collect, use and share your health information.

If you change your mind later and do not want us to collect, use or share your health information, you need to send a letter to the researcher listed on the attached consent form. The letter needs to say that you have changed your mind and do not want this authorization form to be good anymore. Until we get such a letter, we will continue to do the things you said we could in this form. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it.

Any questions? Please ask the researcher. You can also call 215-590-2830 with questions about the research use of your health information. The researcher will give you a signed copy of this form.

SIGNATURE, DATE, AND IDENTITY OF PERSON SIGNING

The health information about _______________________________________ can be collected and used by the researchers and staff for the research study described in this form and the attached consent form.

Signature: ______________________________________ Date:__________________

Print name: ________________________________ Relation: ____________________
INTRODUCTION QUESTIONS

I. I’d like to start by asking you a few questions about yourself.
   A. How old are you?
   B. Do you have any brothers or sisters?
      *If yes: How old are they? Do any of them have CF?*
   C. How long have you been in the hospital this time?
   D. About how many other times have you been hospitalized?
   E. Did you have any experiences with music before music therapy? (lessons, instruments, school music groups)

II. What is it like to be in music therapy?
   *Follow patient’s lead to topic heading.*

III. How else are you able to describe what it is like to be in music therapy?
   *Follow patient’s lead to topic heading.*
   Ask as many times as necessary, until patient can no longer think of new answers.

IV. While you were in music therapy did you notice any changes in …
   (topic headings)
   A. your body
   B. your thoughts
   C. your feelings
   D. the way you feel about being in the hospital
   *Follow patient’s lead to each topic heading. Ask only if necessary, as needed to cover each topic.*

V. Are there any other ways you are able to describe what it is like to be in music therapy?

VI. How would you describe music therapy to a friend?

VII. What was your favorite thing about music therapy?

VIII. Is there anything that you wish you could have changed about music therapy?
IX. These next few questions are just to get some additional information about your music therapy sessions.
   A. Did you ever have music therapy before these three music therapy sessions?
      *If yes:* Can you tell me when and where?
   B. What kind of things did you do in your music therapy sessions?
   C. Were there any other people at your music therapy sessions (such as family members, medical staff, or other patients)?

X. Have I covered everything? Is there anything else I should know about your experience with music therapy?
TOPIC HEADINGS

If topic was initiated by patient use the words “How else” omitting any italicized word(s). If topic is interviewer initiated use underlined sentence.

A. Your body
   1. (How else) Did you notice any changes in your body during the music?
      Ask as many times as necessary until the patient has no new responses.

      *Ask the following questions if they are needed.*

      a. Did the music help you relax?
      b. Did it help you exercise your muscles?
      c. Did you feel like you had more, less, or the same amount of energy right after the session as before it.
      d. Did you notice a change in your breathing during the music therapy?
         *If yes:* How did your breathing change?
      e. Did notice a change in how you felt pain during the music therapy?
         *If yes:* What was different about your pain?
      f. Is there anything else you could tell me about how your body responded to music therapy?

B. Your thoughts
   1. (How else) What kind of things came into your mind during the music?
      Ask as many times as necessary until the patient has no new responses.

      *Ask the following questions if they are needed.*

      a. Did the music remind you of any memories?
      b. Did the music make you think of being somewhere else?
      c. Did you think of any words or pictures during the music?
      d. Did you think of other people while making music?
      e. Is there anything else you could tell me about what came into your mind during music therapy?
C. Your feelings or mood
   1. (How else) Did you notice a change in your feelings or mood during the music?
      Ask as many times as necessary until the patient has no new responses.

      *Ask the following questions if they are needed.*

      a. Did you think about your feelings during the music?
      b. Were you able to talk about your feelings during music therapy?
      c. Did your mood change during the music?
      d. Did you feel less scared during the music?
      e. Did you feel less bored during the music?
      f. Did you feel less lonely during the music?
      g. Is there anything else you could tell me about how your feelings or mood responded to music therapy?

D. The way you think about yourself
   1. (How else) Did you think about yourself in a different way during the music making?
      Ask as many times as necessary until the patient has no new responses.

      *Ask the following questions if they are needed.*

      a. Did you look at things differently during the music?
      b. Did you feel different about your future during the music?
      c. Did you feel different about yourself during the music?
      d. Did you feel differently about being in the hospital during music therapy?
      e. Is there anything else you can tell me about how you thought about yourself during the music therapy?