PSYCHOSOCIAL ASPECTS FOR TEENAGERS AND YOUNG ADULTS WITH CYSTIC FIBROSIS

By

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ABSTRACT

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Cystic Fibrosis, or commonly called CF, has long been known as a childhood disease. Advances in medical technology have prolonged the lives of individuals living with CF. With prolonged life expectancy, new issues are arising that have not been addressed, especially psychosocial concerns. Hanock Livneh and Richard Antonak describe psychosocial adaptation to disability as occurring through a gradual process of assimilation of changes in one's body, body image, ego, self-concept, and person-environment interactions. The current study examined psychosocial adaptation among teenagers and young adults with CF. Psychosocial adaptation to CF was measured among 72 teenagers and young adults age 13 to 22 and over at the University of Minnesota Hospital and Clinic

Pediatric Pulmonary and Critical Care Medicine. Adaptation to CF was measured using an adapted version of Hanock Livneh and Richard Antonak's 1989 survey, *Reactions to Disability and Impairment Inventory (RIDI)*. Questions were also developed by the researcher to examine participants' struggles with CF. Participants were evaluated according to eight levels of functioning (anxiety, shock, denial, depression, externalized hostility, internalized anger, adjustment and acknowledgement). Results indicated that females with CF experienced higher levels of shock compared to males. Individuals with CF who have a good relationship with their siblings showed higher levels of adjustment towards CF. As individuals grow older they have higher levels of acknowledgement. Questions asked by the researcher illustrated that individuals with CF showed an overall positive attitude when dealing with their disability.

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CHAPTER I: INTRODUCTION

"Woe to that child which when kissed on the forehead tastes salty, he is bewitched and soon must die" (Welsh & Smith, 1995, p.52). This adage, from Northern European folklore, is an early reference to the common genetic disease Cystic Fibrosis. Cystic Fibrosis, commonly called CF, is the most common fatal genetic disease in the Caucasian population (Beers & Berkow, 1999). Symptomology of the disease can be dated back to 1905 (Harris & Super, 1995). The name Cystic Fibrosis of the pancreas was first applied to the disease in 1938. The disease shows wide ethnic variation, with prevalence of CF births ranging from 1 in 2,500 for the United Kingdom and Caucasian races to1 in 17,000 for African-Americans, and 1 in 90,000 for Orientals (Bluebond-Langer, Lask & Angst, 2001). Approximately 2,500 babies are born with CF each year in the United States (Healing Well, 2001). Cystic Fibrosis is a genetic disorder, which means that the genes determine if an individual with have CF or not (Orenstein, 1997). The only way to be born with CF is to inherit two abnormal CF genes (one from each parent). Individuals with just one abnormal CF gene are called "carriers", and do not exhibit any symptomology of Cystic Fibrosis. For example, if both parents are carriers of the abnormal CF gene, there is a 25% chance that the child will have CF, a 50% chance they will be a carrier, and a 25% chance they will neither have CF nor be a carrier. There are approximately 10 million Americans who are carriers of the CF gene (McCracken, 1992). Carriers of the

defective CF gene are symptom free, they show no signs that they carry the gene. In the United States, 1 in every 25 people are carriers for Cystic Fibrosis.

Cystic Fibrosis is a generalized, hereditary disorder in which there is widespread dysfunction of the exocrine glands (McCracken, 1992). Exocrine glands are responsible for secreting the products they make into ducts and tubes of the body. Examples of exocrine glands are the sweat glands, salivary glands, the pancreas and sebaceous glands. The basic defect in CF cells is the faulty transport of sodium and chloride (CF Foundation, 1996). Individuals with CF lack a specific gene, which creates a protein. This protein regulates the flow of chloride ions across the cell membrane (CF Web, 2000). A correctly operating chloride channel is important for the functioning of many bodily functions. This improper regulation in CF causes the body to produce abnormally thick, sticky mucus. The abnormal mucus interferes with numerous systems in the body (CF Foundation, 1996). Over time the process of obstruction and inflammation progressively worsens resulting in ongoing destruction of affected organs (McCracken, 1992).

Effects of Cystic Fibrosis on the Respiratory System

Most of the morbidity of CF, and virtually all the mortality, is related to chronic lower respiratory tract infection (Bluebond-Langer, Angst & Lask, 2001). The lungs are the most important affected organs of the body in people with CF, and cause most of the sickness, and more than 95% of the deaths from CF

(Orenstein, 1997). The respiratory tree is lined with small cilia, which are covered in a thin layer of mucus (Harris & Super, 1995). Their job is to move mucus and other matter toward the nose to be removed. Normal mucus is thin and slippery and helps keep the lungs and air passages clean. Individuals with CF produce thick, sticky mucus, which clogs the bronchial tubes in the lungs (Canadian Cystic Fibrosis Foundation, 2002). Mucus that cannot be properly cleared sits and stagnates in the bronchi (airways). "For a child born with CF, their lungs are normal at birth, but the basic defect of CF rapidly results in thick, sticky secretions, recurrent bronchitis and infection, progressing to bronchiectasis and ultimately respiratory and right heart failure" (Bluebond-Langer & Angst & Lask, 2001, p.6). The lung problem is progressive, meaning it will eventually get worse as time goes by (Orenstein, 1997). This thick, viscous, secretion provides an opportunistic environment for the colonization of various bacterial infections. These organisms that cause infections in CF can lead to the destruction of cilia, alter the smooth muscle and elastic tissue, and cause scarring or fibrosis (hence the name of the disease) of lung tissue (McCraken, 1992). The lungs of individuals with CF can act as a petri dish for a wide range of organisms. Harris and Super (1995) commented that a bacterium common to many individuals with CF is Pseudomonas, which is an opportunistic bacterium that looks for weaknesses in the lung tissue before it attacks. "An estimated 80% of all those with CF will become colonized with a certain strain of Pseudomonas Aeruginosa,

virtually specific to CF, mostly before 12 years of age" (Bluebond-Langer, Angst & Lask, 2001, p.6). The organism is difficult to eradicate, and once established in the lungs, can never be eliminated permanently. Conditions in the lungs of those with CF provide the right environment for these and other organisms to thrive (Harris & Super, 1995). A vicious cycle involving obstruction, infection, lung tissue destruction and bronchospasm can be set into motion in CF (McCraken, 1992). Treatment of Cystic Fibrosis is aimed at slowing the progression of the disease. Regular treatment to keep the airways clear of mucus and infection is extremely important, and with very good treatment, the progression of the lung disease can be slowed dramatically, and the lungs can be kept relatively healthy for long periods of time (Orenstein, 1997).

Effects of Cystic Fibrosis on the Gastrointestinal System

One of the major effects of Cystic Fibrosis is on the pancreas (Harris & Super, 1995). Failure to digest and thus absorb nutrients is present in 85 to 90% of individuals with CF (Bluebond-Langer, Angst & Lask, 2001). The pancreas supplies the small intestine with enzymes to assist in digestion. When the opening from the pancreas is blocked by mucus, the enzymes cannot reach the small intestine. As a result, food that passes through the bowels is not fully digested and nutritional value is lost (Canadian Cystic Fibrosis Foundation, 2000). This results in an abnormal loss of vitamins, proteins, minerals, carbohydrates, water and ultimately malabsorption. Treatment for gastrointestinal problems

includes using pancreatic digestive enzymes so food can be properly digested and absorbed (McCracken, 1992).

In addition to producing digestive enzymes, the pancreas produces hormones, especially insulin (Orenstein, 1997). Insulin is needed by the body to move glucose, the body's main simple carbohydrate used for energy, from the blood into the body's cells. When insulin is not produced, as it is needed, diabetes results with elevated blood sugar levels (Orenstein, 1997). Diabetes and glucose intolerance are common in adolescents and adults with CF due to the pancreatic destruction from obstruction and inflammation. Approximately 35% of adults with CF 25 years of age or older will develop CF related diabetes. When presented with Diabetes, the need for more demanding treatment and further restrictions may come as a heavy blow and an additional burden to the person with CF (Bluebond-Langer, Angst & Lask, 2001). The energy requirements are greater for individuals with CF than those without. It is well established that an individual with CF requires significantly more calories than individuals without the disease (McCracken, 1992). This is due to the poor absorption of nutrients even with pancreatic supplements. Individuals with CF are in a constant state of fighting their disease. Individuals with CF require higher energy expenditure during periods of wellness and during periods of illness. An illustration of the increased energy demands comes from the University of Minnesota Hospital and Clinic. A normal male age 16 requires approximately 42

calories per kilogram of energy, compared to a 16-year-old male with Cystic Fibrosis who requires 63 calories per kilogram of energy. Thus this increased energy requirements of CF and the impaired absorption of nutrients mitigate against normal growth in CF (Bluebond-Langner, Angst & Lask, 2001).

Cystic Fibrosis also has effects on the liver. The role of the liver is to produce bile for digestion, detoxify poisons in the body, and store carbohydrates (McCracken, 1992). In individuals with CF, the abnormally thick, sticky mucus plugs the ducts of the liver causing small areas of scarring. Approximately 5 to 10% of individuals with CF demonstrate abnormal liver function and evidence of liver disease.

Effects of Cystic Fibrosis on other systems

The sweat glands of individuals with CF release salt at about 5 times the concentration released by normal sweat glands (CF Web, 2000). Over 99% of people with CF have abnormal sweat (Orenstein, 1997). Normal sweat consists of electrolytes in water being sodium and chloride. In CF, there is a substantial increase of these electrolytes in the sweat. Because of the loss of electrolytes during sweating, individuals with CF must be careful during hot weather, exercise increases the chance of heat exhaustion. Prevention of excessive salt loss is to encourage high concentration of salty foods and plenty of liquids.

A final system affected by CF is the reproductive system. The problem with the reproductive system comes as in all the other systems with the

abnormally thick mucus. In males, the vas deferens is either incompletely formed or totally blocked (Orenstein, 1997). The vas deferens carries sperm from the testicles to the penis. In CF, the sperm is formed, but it cannot be released due to the blockage. This malfunction results in 98% of males with CF being sterile. In women with CF the problems related to the reproductive system are subtler than in men. The main problem for females is the mucus lining the cervix is abnormally thick making it harder for females with CF to become pregnant. Many women with CF have conceived children, but nutrition and pulmonary functioning are vital areas of importance. Women whose lungs are in good shape usually do well with pregnancy; on the other hand women whose lungs are struggling with infection have a harder time at pregnancy.

Statement of the Problem

Cystic Fibrosis used to be considered a childhood disease, when CF was first described in 1938, most infants died before they were a year old. Being born with CF almost certainly spelled early death. Many factors have contributed to the lengthening of lifespan for people with CF. These include a better understanding of the disease itself, the availability of improved antibiotic therapies, improved nutritional support, the availability of innovative therapies, anti-inflammatory agents, and more effective pancreatic enzymes (Slovay Healthcare, 2002). Current predictions of life expectancy suggest that a child born in the 1990's is likely to have a median life expectancy of 40 years of age.

This is remarkably different than the prognosis was even 10 years earlier. Life expectancy by the start of the 1980's was 20 years of age. With these new medical advances an increasing number of individuals with CF now live in relatively good health, well into adolescence and young adulthood (Bluebond-Langer, Angst & Lask, 2001). With this improved life expectancy, there needs to be a focus on the psychosocial functioning of these individuals. The last comprehensive book that focused on psychosocial aspects of CF was published nearly 30 years ago. With improved life expectancy, aspects related to the psychological and social well being needs to be addressed. The overall impact of CF on psychosocial functioning is considerable (Lask, 2001). Psychosocial areas affected by the disease are personal relationships, uncertainty of health status, body image, self-esteem, strict therapy regimens, large amounts of medications, vocational uncertainty, economic pressures, embarrassment, a loss of sense of control and the gambit of emotions experienced. The manifestations of CF have profound effects on all areas of life. It is this researcher's opinion and experience living with Cystic Fibrosis for 26 years that the overwhelming impact that the disease has taken physically that most of the attention of the medical profession has been largely concentrated on physical aspects of the disease. Doctors were forced to combat the medical aspects of the disease because if they didn't, the patient would not survive long with CF. Advances in all forms of treatment and life expectancy now must place the focus of the disease on psychological as well

as the medical aspects. Thus, a holistic approach to treatment would increase both the quantity of life but also the quality. The focus of this research is to look at the psychosocial aspects of chronic illness for teenagers and young adults with CF. This study was conducted at the University of Minnesota Hospital and Clinic at the Department of Pediatric Pulmonary & Critical Care Medicine, Cystic Fibrosis Center. Participants were in the age range of 13 to over 22 years of age, and each had a medical diagnosis of CF. This study was conducted for a two-month period to allow for adequate responses. Individuals were given an opportunity to participate during their scheduled appointments at the clinic for pulmonary function testing. The pulmonary technician administered the surveys to the participants as instructed by the researcher. Participants were given a 57-question inventory that measured individuals' reactions to their disability. This inventory was adapted from an existing inventory developed by Livneh and Antonak (1989) titled *Reactions to Impairment and Disability Inventory (RIDI)*. Adaptations were made to the survey to apply to Cystic Fibrosis. Upon completion of this instrument, participants answered additional questions that pertain to the individuals' own personal experience with CF.

Research Questions

The following questions were of interest in this study.

1. What are the demographic characteristics of survey respondents?

2. Do individuals with Cystic Fibrosis exhibit significant psychosocial reactions to their disability as measured by the RIDI?
3. Do males and females with CF identify different psychosocial reactions to their disability as measured by the RIDI?
4. Is there a correlation between the age of an individual with CF and the type of psychosocial reactions they exhibit as measured by the RIDI?
5. Do individuals with CF who have siblings with CF and individuals with CF that do not have siblings show significant differences to psychosocial reactions as measured by the RIDI?
6. Does the relationship with siblings affect RIDI scores?
7. Who do individuals with CF confide in?
8. What is the average length of time that an individual with CF has been receiving services through the University of Minnesota?
9. How satisfied are individuals with CF with their relationships with the CF care team?
10. How many physical therapies do individuals with CF typically do a day?
11. Is there a tendency for individuals with CF to hide their medications?
12. Are individuals with CF satisfied with their physical stature?
13. Do individuals with CF participate in sports?

Definition of Terms

The following terms are unique to this study and need to be addressed.

Cystic Fibrosis: Cystic Fibrosis is a life-shortening, inherited disorder that affects the way salt and water move into and out of the body's cells. The most important effects of this problem are in the lungs and the digestive system, where thick mucus blocks the small tubes and ducts. The lung problem can lead to progressive blockage, infection, and lung damage, and even death if there is too much damage. The pancreatic blockage causes poor digestion and poor absorption of food, leading to poor growth and under nutrition (Orenstein, 1997).

Psychosocial Problems: The way an individual goes through various stages of development that are both psychological and social in nature, where conflict structures each stage (Perrin, 1993).

Assumptions

It is the researchers assumption that results from this study will provide CF care teams who work with their patients an idea of what reactions they are experiencing with regards to having CF. It is the researchers hypothesis that individuals with CF will have higher levels of anger, depression, denial, shock as measured by the RIDI. Furthermore, individuals with CF will show as an overall group the incredible versatility and overall positive attitude despite the numerous roadblocks faced with having CF. Results from this study will shed light on the emotional and psychological functioning of those with CF.

CHAPTER II: LITERATURE REVIEW

Chronic Illness and Disability

Eight of the ten most common causes of death in the United States are linked to chronic health conditions (Livneh & Antonak, 1997). It is estimated that currently more than 35 million Americans have some form of chronic illness or a disabling condition that interferes with their daily lives. Perrin (1993) defined a chronic health condition as "an illness or impairment that is expected to last for an extended period of time and require medical attention and care that is above and beyond what would be normally be expected for a child or adolescent of the same age, extensive hospitalization or in-home health services" (p.876). Furthermore, The Americans with Disability Act define a disability as a physical or mental impairment that substantially limits one or more major life activities. The World Health Organization also defines disability as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. The typical American can expect to spend twelve years of their lives in a state of "limited functioning" because of a chronic medical condition.

Rando (as cited by Chubon, 1988) suggested that the development of a severe chronic illness results in the need for an individual to modify one's lifestyle to accommodate for the disease, and when the prognosis indicates that the disease will lead to death, it means that the individual must confront and adapt to the realization that life will now be limited. A diagnosis of progressive

deterioration can wreak havoc in the physical, social, vocational and economic areas of life. Treatment regimens, the uncertain prognosis of the illness, the constant psychosocial stressors, the increasing interference with daily life activities, and the effects on the family and friends combine to create a major hardship in the lives of those with chronic illness and disability (Livneh & Antonak, 1997).

Defining Psychosocial Adaptation and Adjustment

There have been numerous researchers who provided their definitions of adaptation and adjustment. Livneh & Antonak (1997) define psychosocial adaptation to chronic illness and disability as:

> "An evolving, dynamic, process through which the individual gradually approaches an optimal state of person environment congruence manifested by active participation in social, vocational and a vocational pursuits, successful negotiation of the physical environment and an awareness of the remaining strengths as well as limitations" (p.8).

Psychosocial adjustment to chronic illness and disability refers more specifically to a particular phase of the adaptation process. Adjustment is seen as the final phase of this process. The individual achieves a state of reintegration, positive striving to reach life goals, positive self-esteem and demonstrating positive attitudes toward oneself, others and disability.

A Model of Psychosocial Adaptation to Illness and Disability

The onset of a chronic illness or disability typically triggers a chain of psychological reactions. Several theoretical models have been proposed to describe a series of psychosocial phases of adjustment to a physical disability (Marnelli & Del Orto, 1991). There has been no clear consensus reached among researchers concerning the nature of the adjustment process to disability. Most authors agree that adaptation is a process of change in reactions that is triggered by external environmental causes, such as injuries or accidents, or internal complications, such as disease (Livneh & Antonak, 1997). According to Marinelli & Dell Orto (1999) there are basic assumptions that are inherent in all stage models of adaptation to a chronic illness or disability:

- In order for the adaptation process to occur, a chronic illness or physical disability must result in permanent and significant changes in functional capabilities.
- Adaptation implies a process of gradual shift from early experiences of distress to reconciliation and acceptance of loss.
- The onset of symptoms of a chronic illness results in temporary loss of psychological equilibrium. Correcting this equilibrium involves a gradual process of reintegration and adaptation to the chronic illness.

- The initiation, progression, and sequence of the phases of adaptation to a chronic illness are internally determined, but external events such as counseling or environmental changes are capable of modifying the structure and pace of the reactions.
- Successful progression through the phases of adaptation produces psychological growth and maturity.
- Reactions to a chronic illness are not universal; each individual's variability influences the ordering of the adaptation phases.
- Individuals with a chronic illness many regress to an earlier phase or skip one or more of the phases to adaptation.
- Each phase of the adaptation process may overlap with another phase. They may blend with one another, providing the experience of more than one reaction at a time.
- Attempts to specify the duration of each phase or the entire process of adaptation are useless.
- Not all individuals with a chronic illness successfully reach the theoretical endpoint of the adaptation process.

Livneh and Antonak's Model of Adaptation to Disability

Livneh and Antonak (1989) designed a unified model for conceptualizing the process of adjustment to physical disability. Each stage of this model contains observed or inferred correlates, feelings within the affective, cognitive, and

behavioral domains. Affective correlates pertain to specific feelings. Cognitive correlates refer to the mental or thought processes. Behavioral correlates refer to the observable activities in which the person engages at the time. Examples of the affective correlate are anxiety and depression. Cognitive correlates include disbelief, confusion and disorganization. Behavioral correlates include social withdrawal, purposeless, and unnecessary risk taking. At the same time, defensive mechanisms operate to avoid anxiety or psychic pain. Examples of defense mechanisms are denial, withdrawal, and repression.

Livneh and Antonak's model consists of five phases. In each of these phases, specific correlates and defensive mechanisms are characteristic in each stage. The first stage of Livneh and Antonak's model is *initial impact*. This stage is the individual's first reaction to encountering a chronic illness or disability. The individual experiences shock and anxiety. At this stage the individual experiencing shock diverts their energy to preserve themselves from overwhelming and painful stimuli (Marnelli & Dell Orto, 1991). Anxiety forms as the individual is gradually exposed to the painful sensations associated with the traumatic event.

The second phase is defensive *mobilization*. The individual regroups their defenses to combat the trauma's devastating initial impact. This stage is composed of two sub stages: bargaining and denial. Bargaining is where the expectancy of recovery signifies a reaction in which the individual hopes for

recovery by negotiating a deal with God to do away with the chronic illness. Denial involves suppressing or negating the disability and its ramifications in order to maintain self-integrity.

The third stage of Livneh and Antonak's model is *initial realization*. In this stage the individual experiences mourning and depression because the reality of the disability and its future implications are now realized. The individual also experiences internalized anger, which is anger that is self-directed and associated with blaming oneself and guilt feelings regarding the onset of the disability or the resulting loss.

The next stage is *retaliation or rebellion*. The individual projects their anger onto the external world in the form of hostility toward other people, objects or environmental conditions. The final phase of Livneh's model of psychosocial adaptation to illness or disability is *reintegration*. There are three sub phases of this stage; *acknowledgement of the disability, acceptance of the disability* and *final adjustment*. Acknowledgement of the disability recognizes the permanency of the impairment and its future implications. These implications include the physical, social, economic, familial and vocational ramifications of the disability. The final two sub stages reflect emotional acceptance of the disability and adjustment to the new life with a disability.

Reaction Phases to Psychosocial Adaptation and Adjustment

Reviews of research concerning psychosocial adaptation to various chronic illnesses and disabilities have most often identified the reaction phases of shock, anxiety, denial, depression, internalized anger, externalized anger, acknowledgement and final adjustment (Livneh & Antonak, 1997). *Shock* refers to the individuals' initial or emergency reaction to the onset of a sudden injury such as amputation or a spinal cord injury to a psychological trauma such as a diagnosis of a life-threatening disease. *Anxiety* as defined by Livneh and Antonak as the panic stricken reaction upon initial sensing of the magnitude of the physical or psychologically traumatic event. Anxiety is most often associated with waiting for results of lab tests, learning about life-threatening diagnosis, anticipation of surgical procedures and contemplating changes in lifestyle. *Denial* is regarded as a defensive mobilization against the painful realization of the extent, duration, and future implications of the chronic disability. An individual experiencing denial is often described as indifferent, aloof and selectively attentive. *Depression* is a reactive response to bereavement for the lost body part or function and the possibility of impending death and suffering. Feelings of hopelessness, isolation, despair and distress are often experienced. *Internalized Anger* refers to the self directed resentment and bitterness associated with self-blame. The physical disability or life-threatening disease is believed to be linked to past transgressions. *Externalized Hostility* is viewed as an attempt to retaliate against the functional

limitations of the illness. The hostility is directed at other people, objects or aspects of the environment believed to be associated with the onset of the disability.

Acknowledgement of the disability is the first indication that the person cognitively reconciled or accepted the permanency of the condition. The theoretical final phase of the adaptation process is *adjustment*. During this phase, the person fully assimilates the functional limitations associated with the illness into a new self that is capable of adjusting to the outside world.

Stages of Terminal Illness

Rando (as cited by Chubon, 1988) outlined a three-phase model depicting the impact of terminal chronic illnesses. The first stage, *acute crisis phase*, is a time when the individual experiences a period of emotional turmoil which is characterized by high levels of anxiety and stress, panic, feelings of helplessness, confusion, and a sense of inadequacy. This high level of stress is dealt with by the mind using defense mechanisms to blunt the impact. One such defense mechanism is denial. Denial is an unconscious defense mechanism marked by refusal to acknowledge painful realities, thoughts, or feelings. Denial may be crucial to sustaining the individual at a reasonable functional level, but in extreme forms, it may be a life threat if it results in the person not committing to treatment. The second phase of terminal illness is the *living-dying phase*. In this phase, the individual searches for self-control and identity. Profound life-style changes

reorganization of body image and self-concept, and confrontation by a barrage of decisions must be addressed. Sooner or later there comes a point where a person with a chronic condition must deal with death. The final phase or *terminal phase*, comes about when available treatments are no longer sufficient to forestall the fatal aspects of the disease process or when the person chooses to forgo the struggle of existence. The individual may ruminate feelings of guilt or regret.

Psychosocial Reactions to Disability and Illness

Few words or feelings are adequate to express or capture the overwhelming sorrow, pain, anger, disappointment, optimism and hope experienced and shared by persons and families changed and challenged by the impact of an illness (Dell Orto, 2002,). Childhood chronic illness can severely impair psychosocial functioning and impede growth (Marnelli, 1999). Steinberg (as cited by Chirico, 2001) defines psychosocial problems as a way an individual goes through various stages of development that are both psychological and social in nature. Adolescence is a stage of life when the individual is undergoes rapid, physiological and psychological changes. Marinelli and Dell Orto (1991) noted that psychosocial tasks needed to leading a productive, psychologically healthy life include adjustment to physical and physiological changes of puberty and the accompanying flood of emotions; the establishment of effective social and working relationships; achievement of independence from primary caretakers', preparation for a vocation and a movement toward a sense of values; and a sense

of definable identity. Difficulties in overcoming the challenges of chronic illness can result in significant emotional disorder, psychosocial impairment, and developmental delay (Marinelli & Dell Orto, 1999). In addition to whatever physical suffering may occur from a chronic disease, the problem has a profound impact on the psychosocial aspects of the person's life, functional level, autonomy, productivity and interpersonal relationships are all affected (Chubon, 1988). Individuals with a chronic illness who do manage to establish some normalcy accomplished it with great struggle at best.

Body Imagery

Physical characteristics receive particular attention during adolescence. Research notes that adolescents are more concerned about their physical appearance than about any other aspect of themselves (Marinelli & Dell Orto, 1991). Body imagery has been linked to self-concept, self-esteem and ones personal and interpersonal identity (Marinelli & Dell Orto, 1999). The early adolescent wants to avoid being "different" at all costs; particularly because of physical appearance, body image, and peer-group conformity are important aspects of self-esteem. Chronic illness and disability can alter one's body image and self-concept because changes that occur need to be accommodated by the individual (Marinelli & Dell Orto, 1999). Several investigators have found that chronically ill and disabled adolescents are more likely to be dissatisfied with their physical appearance than are their physically healthy counterparts. Adsett,

Kellerman and Katz (as cited in Marinelli & Dell Orto, 1991) observed that individuals who were disfigured from cancer therapy had a greater fear of unacceptability and isolation secondary to their disfigurement than of death itself or of a recurrence of the illness. Adolescents with relatively no visible conditions are also likely to have impaired body images because some conditions may result in delays in physical growth and in the appearance of secondary sexual characteristics.

Peer Relations

The school has a tremendous influence on the psychosocial functioning of adolescents. The disability an adolescent faces will affect academic functioning, and color the psychosocial experience by influencing daily functioning, self-esteem, emotional status, and social development (Marinelli & Dell Orto, 1999). During adolescence, relationships between both same and opposite sex peers come closer to serving as prototypes for later adult relationships in both social and professional relationships (Marinelli & Dell Orto, 1991). The peer group can have a significant effect on how the adolescent defines their identity. In addition to the psychological trauma, which is caused by terminal chronic illness, the individual also faces a "social death" (Chubon, 1988). The fact of terminality or irresolvable serious illness has been found to have a profound impact on the ill person's social relationships. The few studies in which the peer relationships of chronically ill or disabled adolescents have been examined suggest that these

adolescents express great concern about their social relationships (Marinelli & Dell Orto, 1991). When individuals are labeled as defective, they are devalued, and perceived as being less attractive and competent. Good medical care requires that a bio-psychosocial approach because biological, psychological, and social factors influence one another and can have a large influence on the child's ability to grow (Marnelli and Dell Orto 1999). The prevention of psychosocial complications of childhood chronic illness will be met best by a family and community centered approach in which the pediatrician assesses the skills and needs of the child and family, participates in planning and implementing comprehensive intervention programs, and supports families in the complex task of raising children and adolescents with chronic conditions (Perrin, 1993).

Psychosocial Aspects for Individuals with Cystic Fibrosis

"We have to remember that people with CF are people first and not a disease". This quote from Barbero illustrates his feelings that there needs to be a study of the psychosocial aspects of CF as well as the medical. The overall impact of CF on psychosocial functioning is considerable (Lask, 2001). Finding out that a child has CF is difficult for all concerned, the child, the parents, and other family members (Canadian Cystic Fibrosis Foundation, 2000). CF has shown to have a tremendous influence in areas like school, strict therapy regimens, economic pressures, a heightened awareness with regard to sickness, a loss of sense of control, uncertainty of health status, peer relations, independency

and autonomy, extra-curricular activities, sports, family life, medical community and self-esteem. Barbero (2001) has identified a number of important obstacles that make it difficult for the individual with CF to adapt and accept the illness. One of the most prevalent barriers to CF includes vocational planning. Twenty percent of individuals with CF experience progressive or perceived disability that limits normal vocational aspirations. A rigorous regimen of therapy requires time, knowledge, and commitment to attain a functional state of well-being. About twenty percent of CF individuals refuse to accept their condition and avoid therapeutic interventions. Approximately forty to fifty percent of individuals with CF have moderate to high economic costs to maintain the intense therapeutic program.

Nutritional and Physical Health

Good nutrition is of major importance in the long-term survival for individuals with CF. Treatment aimed at achieving an ideal nutritional status is an integral part of the management of patients with CF (Abbott, et al., 2000). Individuals with CF are usually under weight. Due to the extra energy requirements to combat the illness, malnutrition may become increasingly apparent as the demands of the pubertal growth spurt outstrip the ability to ingest enough food (Bluebond-Langner, Angst & Lask, 2001). Approximately thirty-three percent of individuals with CF in North America are below the twenty-fifth percentile for weight. Nutritional status is highly correlated with the progression

of lung disease, recovery from sickness and life expectancy. CF patients who have better nutrition grow better, have better lung function, and live longer than patients with poor nutrition (Orenstein, 1997). Eighty five percent of patients with CF have pancreatic insufficiency resulting in malabsorption of nutrients, especially fats. To combat this pancreatic insufficiency, most people with CF need to take pancreatic enzymes to digest their food. For individuals with CF, the adolescent years are a time when health begins to deteriorate. Bluebond-Langner, Angst & Lask (2001) cite McCracken who observed that at a time when adolescents become increasingly interested in their bodies and appearance, the adolescent with CF spends much energy attempting to hide the physical stigma of the disease (delayed growth). According to Abbott, et al., 2000, more problems with food/eating behavior were associated with less body satisfaction and reduced self-esteem. Boyle, Di Sant Agnese, Sack, Millican, and Kulczycki, McCollum and Gibson (as cited in Bluebond-Langner, Angst & Lask, 2001) determined that retardation in growth and sexual development contributed to peer-group rejection of adolescents with CF.

Family Dynamics

Family relationships play a critical role in health outcomes for the individual with CF (Bluebond-Langner, Angst & Lask, 2001). A chronic life-threatening illness like CF makes significant intrusion on family life (Bluebond-Langner, 1996). Early research on families with CF found that they were viewed

as dysfunctional due to financial and social stresses, parental over protectiveness, isolation, decreased family satisfaction and feelings of child and parent guilt, anxiety and depression. Recent research observed that while all families struggle with the onset and the demands of the illness, the vast majority of these families do not exhibit patterns of deterioration or dysfunction. Many families showed considerable resilience to adapt to this stressful situation (Bluebond-Langner, Angst & Lask, 2001). In her book, *In The Shadow Of Illness: Parents And Siblings Of The Chronically Ill (1996)*, Bluebond-Langner uses the myth of Sisyphus to illustrate the endless, hopeless labor that CF can have on a family. Sisyphus was condemned by the gods to push a huge bolder up a hill, once he reached the top, the boulder would fall back to the ground. Many of the CF families that Bluebond-Langner has encountered in her book suffer this fate. The diagnosis of CF causes a number of emotions, shown in statements such as "I can't believe this"; "What will the future hold?", "Could I have done anything different?". Orenstein (1997) noted that families go through a grieving process; the parents mourn the loss of a healthy child as they expected. Because of the unpredictability of CF, families go through a number of phases in the course of the illness. This unpredictability can occur the first year of diagnosis, to the first exacerbation of the disease, requiring hospitalization, to the increasing deterioration and complications to ultimate terminality. Another important area with regard to family functioning is the well sibling in the family. CF can impose

incredible demands on the parents of the child with CF. The child will require the parents' time and affection as well as a great deal of resources, in terms of finances and time. Research has shown that growing up with a sibling who has CF can be both a positive and a negative experience. Negative research on the effects of living with a chronically ill sibling showed a number of problems with the well sibling. These included behavior problems, irritability, aggressiveness, anxiety, poor school performance and depression. At the other end of the spectrum, some studies find that chronic, life-threatening illness may actually have positive effects on the well sibling (Bluebond-Langner, Angst & Lask, 2001). Kupst (as cited by Bluebond-Langner, Angst & Lask, 2001) found that well siblings of children with cancer became "more compassionate, tolerant, empathetic and appreciative of their own health. Walker (as cited in Bluebond-Langner, Angst & Lask, 2001) found positive effects such as increased ability for empathy and sensitivity, enhanced personal maturation and self-concept, an increase in family cohesion, and a perceived ability to cope with negative changes.

Growing up with Cystic Fibrosis

The teenage years are a crucial time for Cystic Fibrosis patients' health (Orenstein, 1997). The adolescent with CF faces many additional physical, social and psychological challenges. Individuals with CF must do often increasingly time-consuming physical therapy treatments to slow the progression of the

disease. This can be especially tough for all involved including the parents who must give up their time, to the adolescent who must find time in their busy schedule. The potential amount of time devoted to the physical therapy treatments is enormous. For example, by the time the individual goes off for school they may have done 45 minutes of nebulized antibiotics, and chest physiotherapy. This takes out a great deal of time for the adolescent who could be participating in extra-curricular activities, socializing with friends, or using the time on other activities. Socialization and peer relationships are very important to adolescents (Bluebond-Langner, Angst & Lask, 2001). The individual with CF is at an added disadvantage. LiPuma et al (as cited in Bluebond-Langner, Angst & Lask, 2001) found that individuals with CF may not come into contact with other individuals with CF. This is due to the bacterial resistance of the organisms that individuals with CF grow. One such organism is Burkholder Cepacia, which can cause significant health decline. The elimination of social opportunities with others who have CF is a significant loss. The school experience for individuals with CF can be challenging. Many questions arise for someone with CF including issues of disclosure, medication, and openness about the disease. All these questions can be tough on an adolescent. Having a higher level of psychosocial support emerged as a strong predictor of better psychological functioning (Chest, 2001). Friends can help manage life's struggles and assist in the progression of life's tasks (Bluebond-Langner, Angst & Lask, 2001). Peer relationships promote

both the development of appropriate social skills and the acquisition of a healthy self-concept. Christian and D'Auria (as cited in Bluebond-Langner, Angst & Lask, 2001) found that good friends were a critical source of support for children growing up with CF, and allowed them to minimize their visible differences from others. Individuals with CF also have to deal with issues regarding small stature. Many individuals with CF are smaller than their classmates due to poor absorption of food. Sinnema et al (as cited in Bluebond-Langner, Angst & Lask, 2001) looked at issues of adolescent independence, conflict resolution, responsibility for health and body hygiene, social activities, sexuality and the development of ideals. They found that individuals with CF scored less well then healthy adolescents in areas of social activities and sexuality and it appeared that delayed puberty and short stature influenced the observed differences.

Adolescence is often known as a time of rebellion. Adhering to the intense treatment required to stay healthy with CF can be challenging. Desmond et al (as cited in Bluebond-Langner, Angst & Lask, 2001) found that missing physical therapy will not make any significant immediate difference, yet after three weeks; measurable deterioration in lung function can be detected. Adolescents need to be responsible for their own treatment and take an active role in their treatment. Bluebond-Langner, Angst & Lask, (2001) comment that a study done in England in 1990, called the Trent study, was based on interviews with 82 adolescents with CF. Adolescents and adults were asked to complete a "worry" score by rating a

number of concerns on a four point scale, ranging from “not worried” to “extremely worried”. The major worries expressed by those with CF were the possibility of an early death, breathlessness, and keeping a job. Durst et al (2001) identified the major themes that individuals with CF found important, they were a strong desire to set and attain meaningful long range goals, the need to control as many aspects of their lives as possible while dealing with over protectiveness, and the adjustment to a new lifestyle. Lask (2001) reports that future psychosocial studies need to anticipate and identify poor adherence to treatment regimen, confirm that family dynamics and relationships affect the course of the illness, confirm that psychosocial interventions do contribute toward an improvement in the course of the illness. Barbero (2001) once asked adults with CF over the age of 35 what advice they would offer youngsters with CF. They commented that individuals with CF should pick a vocation, that is clean and non-polluting, and also look for good insurance. They also mentioned to take good care of yourself, and to not hide your CF.

CHAPTER III: METHODOLOGY

Introduction

The purpose of this study was to examine the psychosocial aspects of Cystic Fibrosis in teenagers and young adults. This chapter will introduce to the reader the methodology of this experiment. Sections addressed include subject selection and description, instrumentation, data collection procedures, data analysis and limitations.

Subject Selection and Description

Subjects for this study were located at the University of Minnesota Cystic Fibrosis Critical Care Clinic. This center was selected because of the researcher's close familiarity with the facility and staff. Participants must have had a medical diagnosis of Cystic Fibrosis to participate in this study. Male and female subjects were included in the study. The age ranges included 13 to 22 and over. Ages were limited to 13-22 because it was felt that children under the age of 13 might not be able to comprehend the survey or demographic questions. The age was set at over 22 because the focus of the research is on teenagers and young adults. These age standards provide a perspective of someone with CF going through the school years and also individuals who have gone through school already. A child assent form was designed for the subjects, and a parental consent form was designed to gain approval for the parent's child to participate.

Instrumentation

The instrument that was selected for this study is from Livneh and Antonak's (1989) *Reactions to Disability and Impairment Inventory (RIDI)*. The Reactions to Disability and Impairment Inventory contains 60 questions pertaining to a list of possible reactions to the occurrence of a physical impairment or a disabling condition. The subject must decide how often they experience each possible reaction to disability from never occurring, rarely occurring, sometimes occurring, or occurring often. Rarely occurring is defined as experiencing a thought 1 to 4 times a month. Sometimes occurring is defined as experiencing a thought 6 to 10 times a month. Often occurring is defined as experiencing a thought more than 10 times a month. Based on subjects responses they will be compared to each of the RIDI's stages of adjustment (shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgment, and adjustment). This researcher modified this instrument by withdrawing three questions on the survey. The first question left off was "Since I became physically impaired, I have periods of hot or cold spells". The second question, "Since I became physically impaired, I have periods of nausea". The final question, "Since I became physically impaired, I have periods of breathlessness". The reason for leaving these questions out was because they had ambiguous meanings. For example, breathlessness could result from panic, but also could mean physical symptoms of cystic fibrosis. Small portions of the questions were

tailored to cystic fibrosis. For example, these questions were altered from, “Since I became physically impaired, I am less interested in other people” to “Having cystic fibrosis has made me less interested in other people”. A large portion of the changes involved the words, “As my disease has progressed”, and the addition of cystic fibrosis instead of physical impairment. *Reactions to Impairment and Disability Inventory* provides the researcher a more useful multidimensional measurement to explore adaptation to disability (Livneh & Antonak, 1997). Administration of this survey to various samples found that the eight subscales were reliable (Cronbach coefficient alpha values of .79 .83 .64 .88 .81 .84 .78 .89). Multiple regression analyses revealed that chronicity was the best predictor for all non-adaptive reactions. Preliminary results illustrate that the RIDI’s homogeneity, specificity, and content and construct validities and supportive evidence for the multidimensional structure of the inventory.

Data collection

A 57-question survey adapted from Livneh and Antonak's *Reactions to Impairment and Disability Inventory (RIDI)* was administered to teenagers and young adults aged 13 to 22 and over at the University of Minnesota Hospital and Clinic. Participants were solicited during their attendance at the clinic for their pulmonary function test. During this time, a pulmonary lab technician provided the participants an assent form for the children under age and the consent form for the parents. Once the parents have read through this and agreed to allow their

child to participate, the survey and demographic questions were administered to the teenager or young adult. Once completed, participants placed their survey in a sealed envelope and place it in a locked box stored within the Cystic Fibrosis clinic. The pulmonary lab technician was given a script to follow every time a new subject took the survey. Direct training was provided to the pulmonary lab technician on how to administer and collect data and handle any questions that may arise.

Data Analysis

A number of statistical analyses were used in this study. The Statistical Program for Social Sciences, version 10.0, (SPSS, 2002) was used to analyze the data. Once the data was received from the University of Minnesota Hospital and Clinic, it was taken to a research and statistical consultant at the University of Wisconsin-Stout. Statistical tests were performed using the .05 & .01 (alpha) level of significance.

The primary research questions of this study were:

Research Question One: What are the demographic characteristics of survey respondents?

Measures of central tendency (frequencies, mean, median) were complied as well as measures of dispersion (variance and standard deviation).

Research Question Two: Do individuals with cystic fibrosis exhibit significant psychosocial reactions to their disability as measured by the RIDI?

Independent Groups T-Test analyses and One-Way Analysis of Variance analyses were used to determine if individuals with CF exhibit significant psychosocial reactions to their disability as measured by the RIDI.

Research Question Three: Do males and females with CF identify different psychosocial reactions to their disability as measured by the RIDI?

Independent Groups T-Test analyses were conducted to examine the relationship between psychosocial reactions as measured by the RIDI and how males and females differ.

Research Question Four: Is there a correlation between the age of an individual with CF and the type of psychosocial reactions they exhibit as measured by the RIDI?

A One-Way Analysis of Variance with a Student Newman-Keuls Multiple Range Test analyses were used to investigate if there was any significance between the age of an individual with CF and psychosocial reactions exhibited.

Research Question Five: Do individuals with CF who have siblings with CF and individuals with CF that do not have siblings show significant differences to psychosocial reactions as measured by the RIDI?

Independent Groups T-Test analyses were conducted to examine the relationship between psychosocial reactions as measured by the RIDI and how individuals with CF who have siblings with CF and individuals with CF who do

not have siblings with CF experience psychosocial reactions as measured by the RIDI.

Research Question Six: Does the relationship with siblings affect RIDI scores?

Independent Groups T-Test analyses were conducted to examine the relationship between psychosocial reactions as measured by the RIDI and how individual's relationships with their siblings affect RIDI scores.

In addition, a series of questions were asked that requests information about the person's own experience with CF.

Research Question Seven: Whom do individuals with CF confide in?

Research Question Eight: What is the average length of time that an individual with CF has been receiving services through the U of M?

Research Question Nine: How satisfied are individuals with CF and their relationships with the CF care team?

Research Question Ten: How many physical therapies do individuals with CF typically do a day?

Research Question Eleven: Is there a tendency for individuals with CF to hide their medications?

Research Question Twelve: Are individuals with CF satisfied with their physical stature?

Research Question Thirteen: Do individuals with CF participate in sports?

Limitations

There are four major limitations to this study. The researcher was not present at the site of investigation. Due to the fact that the researcher attended school at the University of Wisconsin-Stout in Menomonie, and the site of investigation was at the University of Minnesota, it will be somewhat difficult to coordinate events. A second limitation was the breaking of standardization of the survey instrument. The reasoning behind the breaking of standardization was some of the questions in this survey did not apply to CF, or they had ambiguous meaning. A third limitation to this study was that there was no control group to compare results with the CF group. A control group would strengthen the findings of this study. A final limitation to this study is the researcher's own bias. The researcher was born with CF and this study may color the results because of the researcher's personal experiences.

CHAPTER IV: RESULTS

Introduction

The purpose of this study was to investigate the psychosocial aspects of teenagers and young adults with cystic fibrosis. This chapter will include the results of the study. Demographic information and item analysis will be discussed. The chapter will conclude with the specific research questions under investigation.

Research Questions

Question #1: What are the demographic characteristics of survey respondents?

A total of 72 participants were used in data analysis. Of the 72 participants, 52.8% (n=38) were male, while 47.2% (n=34) were female. Age was categorized into 4 groups: 13-15, 16-18, 19-21, and 22 or older. Table 1 shows the breakdown of age groups and the number of subjects within each age category.

Table 1

Age Categories

Age Bracket	Frequency	Percent
13 – 15 year olds	13	18.1%
16 – 18 year olds	15	20.8%
19 – 21 year olds	17	23.6%
22 and older	27	37.5%

A vast majority of participants (n=70; 97.2%) were not married. Participants were also asked about their number of siblings with and without CF. Seventy

participants indicated they had at least one sibling in their family, (n=22; 30.6%) of which have CF. The average grade level completed by the participants was 12th grade (12.06). Table 2 illustrates the grade level of each participant.

Table 2
Highest grade level completed by respondent

Grade Level	Frequency (N=72)	Percent
6th grade	4	5.6
7th grade	3	4.2
8th grade	2	2.8
9th grade	5	6.9
10th grade	6	8.3
11th grade	7	9.7
12th grade/GED	14	19.4
1 year post HS	10	13.9
2 years post HS	5	6.9
3 years post HS	1	1.4
Bachelors degree	13	18.1
5 years post HS	2	2.8

Question #2 Do individuals with Cystic Fibrosis exhibit significant psychosocial reactions to their disability as measured by the RIDI?

It is important to note that instrument Reactions to Impairment and Disability Inventory (RIDI) is strictly an experimental tool for researchers; attempts at using this as a diagnostic instrument are unwarranted (Livneh & Antonak, 1997). Participants were asked to read each question and respond whether they have experienced this thought never, rarely, sometimes, or often. "Rarely" is defined as experiencing a particular thought 1 to 4 times per month,

"Sometimes" is defined as experiencing a particular thought 5-10 times per month and "Often" is defined as experiencing a particular thought 10 or more times per month. Participants' responses were then categorized into eight subscales: shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement, and adjustment. Measures of central tendency and variability were examined. The following survey items were found significant by this researcher.

One area of significance was survey item number twenty-one "I am certain that I will be completely cured". Table 3 notes that there are a wide variety of responses for this question. 36.1% (n=26) feel they will never be completely cured, while 11.1% (n=8) often think this statement. This illustrates the frustration observed by those who feel that in their lifetime a cure will not be found or if there is a cure found it will be too late for them.

Table 3
I am certain that I will be completely cured.

Item response	Frequency (N=72)	Percentage
1 Never	26	36.1%
2 Rarely	23	31.9%
3 Sometimes	15	20.8%
4 Often	8	11.1%

Another area of significance noted was with survey item number thirty-eight "I do not mind accepting help when I need it". Table 4 shows a wide

variation in the responses. 36.1% (n=26) say that they do not mind accepting help when they need it, while 11.1% (n=8) of respondents say they do mind having someone help them when they need it. Participants who feel that they don't want help may be experiencing some rebellion toward authority and want to do things their own way.

Table 4
I do not mind accepting help when I need it.

Item response	Frequency (N=72)	Percentage
1 Never	8	11.1%
2 Rarely	12	16.7%
3 Sometimes	26	36.1%
4 Often	26	36.1%

Significance was noted on survey item number forty-two "I am impatient with medical treatment recommended for me". This question was dispersed near equally for a number of the responses. Table 5 shows that 39.4% (n=28) never feel impatient with the medical treatment recommended for them, while a quarter of the respondents 25.4% (n=18) feel impatient 5 to 10 times a month. Due to the incredible workload that is necessary to maintain health for individuals with CF, impatience can occur often especially with individuals who are trying to fit in with school and other responsibilities.

Table 5
I am impatient with medical treatment recommended for me.

Item response	Frequency (N=71)	Percentage
1 Never	28	39.4%
2 Rarely	21	29.6%
3 Sometimes	18	25.4%
4 Often	4	5.6%

Survey item number forty-three "I realize that my physical impairment is part of me, but I do not let it interfere with my life". Table 6 highlights a large portion of the sample 57.1% (n=40) say they often feel that their impairment is a part of them, but they don't let it interfere with their life. A high number 12.9% (n=9) on the other spectrum say that cystic fibrosis does interfere with their life. It is interesting to note that individuals who say that they don't let CF interfere with their life may be experiencing some denial about their disability. CF treatment requires a significant amount of time and energy and if this treatment is done, it will interfere with an individual's life.

Table 6
I realize that my physical impairment is part of me, but I do not let it interfere with my life.

Item response	Frequency (N=70)	Percentage
1 Never	9	12.9%
2 Rarely	6	8.6%
3 Sometimes	15	21.4%
4 Often	40	57.1%

Survey item number forty-seven “I believe that nothing is wrong with me”. Table 7 shows that a large portion of the sample 40.3% (n=29) feel that there is something wrong with them, while 18.1% (n=13) often think that nothing is wrong with them. The individuals who feel that there is something wrong with them are acknowledging that they do have a life-threatening illness and it does impose limitations on them. Individuals who think that nothing is wrong with them may be experiencing some form of denial about the magnitude of their illness.

Table 7
I believe that nothing is wrong with me.

Item response	Frequency (N=72)	Percentage
1 Never	29	40.3%
2 Rarely	11	15.3%
3 Sometimes	19	26.4%
4 Often	13	18.1%

The following are a list of the remainder of the questions from the survey.

Survey Item number one asked “Having cystic fibrosis has made me less interested in people”. Fifty-six respondents or 78.9% say that CF has not made them less interested in other people. The second survey item asked, “If I become a better person, my disease will be cured”. Fifty-nine respondents or 81.9% feel that they will not be cured if they become a better person. The third survey item asked, “As my disease has progressed, I cry more often”. Forty-six respondents

or 63.9% say that they do not cry more often as their disease progresses, while eighteen respondents or 25% have experienced crying 1 to 4 times a month because of their disease progression. The fourth survey item asked, "When I look back on what has happened to me, I feel bitter". Thirty-five respondents or 48.6% say they never feel bitter about what has happened to them, while twenty-nine respondents or 40.3% say they have experienced bitterness rarely or 1 to 4 times a month. Item number five "God will cure me if I improve my behavior and follow his ways". Forty-eight respondents or 67.6% (n=48) respond that they never feel that if they improve their behavior god will cure them. Fourteen or 19.7% of participants responded that they experience this reaction rarely. The sixth survey item number asked if "I am a failure as a person". Fifty-nine respondents or 81.9% of subjects never feel that they are a failure. Item number seven asked, "I am satisfied with my present abilities despite my physical impairment". A vast majority of participants, forty-six or 64.8% responded to this statement as often and feel that they are satisfied with their abilities despite their impairment. The eighth survey item asked, "As my disease has progressed, I have attacks of panic". Fifty participants or 69.4% never experience attacks of panic, although nineteen participants or 26.4% experience panic 1 to 4 times a month. The ninth survey item asked, "My disease must be a punishment for something I did in the past". A majority of subjects sixty-six or 91.7% have never felt that their disease is a punishment for something they did in the past. Item number ten

asked if "I am embarrassed about having cystic fibrosis". Half of the respondents or thirty-six individuals felt they were never feel embarrassed about having CF. Twenty-seven or 37.5% rarely feel this statement is true. It is interesting to note that eight respondents or 11.1% of subjects experienced embarrassment as often as 5 to 10 times a month. Item number eleven asked if "There are more important things than those that my disease prevents me from doing". Responses to this question were dispersed out compared to past questions. Thirty-three respondents or 45.8% of respondents often feel that there are more important things than what CF prevents them from doing. An alarming twelve respondents or 17.1% felt that CF prevents them from important things in life. The twelfth survey item asked if "I have difficulty finding a reason to get up in the morning". Fifty-one or 70.8% of subjects never have difficulty finding a reason to get up in the morning, while fifteen subjects or 20.8% experienced difficulty getting up in the morning rarely. The thirteenth survey item asked, "If I were a nicer person, I would regain my abilities". Sixty-four participants or 88.9% of respondents never feel that if they were a nicer person they would regain their lost abilities due to CF. Item number fourteen asked if "I am rearranging some of my life priorities". Twenty-eight respondents or 39.4% felt that they are rearranging their life priorities and think this 5 to 10 times a month. The fifteenth survey item asked, "Although I am restricted to certain ways, there is still much I am able to do". Fifty-two respondents or 73.2% of respondents believe that there is still much they can do

despite some limitations. Item number sixteen asked if "My life is empty". Sixty respondents or 83.3% of respondents never feel that their life is empty. The seventeenth item asked if "I find myself trembling without any apparent reason". Sixty-one participants or 84.7% document that they never find themselves trembling without any reason. The eighteenth survey item looked at whether "It makes my blood boil to have someone talk about my disease". Fifty-two respondents or 72.2% felt like their blood boils when someone talks about CF, while sixteen or 22.2% of the sample felt like their blood boils when others talk about CF. The nineteenth survey item looked at whether "Living through cystic fibrosis, I feel I understand things better". Twenty-nine respondents or 40.3% of the sample often felt that they understand things better living with CF, while twenty-eight respondents or 38.9% sometimes feel that they understand things better. Item number twenty asked, "I feel nothing will ever be the same again". A large portion of the sample forty-one respondents or 58.6% of the sample never feel like things will be the same again, but a surprisingly high eight participants or 11.4% feel that things will never be the same.

The twenty-first survey item asked, "When I look at other people, I am eaten up with jealousy". It is surprising to note that fifty-one participants or 70.8% never feel eaten up with jealousy. Item number twenty-three asked, "I am so restless that I cannot sit still". A large majority of the sample forty-nine or 68.1% never feel so restless that they cannot sit still, while 31.9% feels that

sometimes they cannot sit still. The twenty-fourth survey item asked, "Nobody is going to tell me what to do". The results of this data are dispersed evenly throughout the spectrum. Twenty-one respondents or 29.6% never think this statement. On the other hand, fourteen respondents or 19.7% of the sample that no one will tell them what to do. The twenty-fifth survey item asked, "I get mad enough to smash things". Forty-four respondents or 61.1% never feel that they get mad enough to smash things. Fourteen participants or 19.4% sometimes feel that they get mad enough to smash things. The twenty-sixth survey item asked, "When I look in the mirror, I see myself and not a disability". Fifty-one respondents or 70.8% felt that they see themselves first and not the disability. This question shows the positive thinking of many of the respondents. The twenty-seventh survey item asked, "My mind goes blank". Thirty-four respondents or 47.9% never feel that their mind goes blank, while twenty-four participants or 33.8% rarely feel it applies. Item number twenty-eight asked, "I feel lonely even when I am with my friends". Nearly half of the respondents thirty-three never feel lonely when with their friends. It is interesting to note that thirty-five or 48.6% of respondents rarely or sometimes feel lonely when with their friends. Item number twenty-nine asked, "Everything in my life is coming together again". This question shows wide variation with twenty-eight respondents or 40.6% stating that they sometimes feel that everything in their life is coming together. An alarmingly high thirteen respondents or 18.8% never

think that things are coming together in their life. Item number thirty asked, “I blame myself for what has happened to me”. Sixty-six respondents or 91.7% of the sample never blame themselves for what happened to them. This shows the positive thinking of many cystic fibrosis youth. The thirty-first survey item asked, “I find myself asking why did this happen to me”. Forty-one individuals or 75% rarely to never feel them asking why did this happen to me. Item number thirty-two asked, “I feel frozen, unable to move”. Sixty-five individuals or 90.3% never felt frozen or unable to move. The thirty-third survey item asked, “I am seeking a new meaning for my life”. Thirty-one respondents or 43.1% never feel like seeking a new meaning for their life, while nine individuals or 12.5% often feel like seeking a new meaning for their life. Item number thirty-four asked, “I am interested in getting socially involved with others”. A resounding 93.1% or sixty-seven respondents often or sometimes feel like getting socially involved with others. The thirty-fifth survey item asked, “I feel there is nothing I can do to help myself”. Forty-five participants or 62.5% never feel that there is nothing they can do to help themselves, while sixteen individuals or 22.2% experience this thought rarely. The thirty-sixth survey item asked, “I cannot believe that this is happening to me”. Forty-seven or 66.2% responded by never experiencing this thought, showing that they are coming to terms and acknowledging the idea that they have CF. The thirty-seventh survey item asked, “I got a raw deal out of life”. Forty-seven respondents or 65.3% say they never feel like they got a raw deal out

of life. Item number thirty-nine asked, “I will soon be just as I was before”. Sixty-one individuals or 88.4% responded that they felt that they would soon be just as they were before rarely to never. Item number forty asked, “As my disease progresses, I have periods when my heart pounds”. Sixty-five individuals or 90.3% rarely to never feel as if they have periods when their heart pounds. The forty-first survey item asked, “I think this is a nightmare and I will soon awaken”. A surprisingly high number of respondents (65 or 90.3%) never feel like they are experiencing a nightmare. Item number forty-four asked, “I feel like getting even with someone”. Fifty-four or three quarters of the sample never feel like getting even with someone, but about 1 out of 10 individuals 9.7% (n=7) often feel like getting even with someone. The forty-fifth survey item asked, “I feel like screaming at others”. Thirty-eight respondents or 52.8% of the sample say that they never feel like screaming at others. Nine individuals or 12.5% of respondents sometimes feel like screaming at others. Item number forty-six asked, “I feel confused about what is happening to me”. Forty-seven individuals or 65.3% never feel confused about what is happening while fourteen individuals or 19.4% rarely feel confused. The forty-eighth survey item asked, “I am interested in forming new relationships”. Fifty-two participants or 72.2% of this sample is interested in forming new relationships. This shows the positive attitudes of many individuals with CF. Item number forty-nine asked, “I believe my disease will go away by itself”. Sixty-three individuals or 87.5% of the

sample never believes that the disease will go away by itself. This alludes to the idea that many people realize that they will be stuck with CF for most if not all of their lives. The next survey item number fifty asks, “Having cystic fibrosis has caused me to have nightmares”. A surprising sixty-one respondents or 85.9% say that they never experience nightmares as a result of CF. The next survey item number fifty-one asks, “I find myself arguing with more people”. Forty-four individuals or 62% never feel like they are arguing with more people, while twenty-four or 33.8% feel that they either rarely do or sometimes argue with others. The fifty-second survey item asked, “Despite my physical impairment, I can do most things non-impaired people can do”. A surprisingly healthy fifty-three respondents or 73.6% of respondents often feel they can do most things non-impaired individuals can do. The next survey item number fifty-three asks, “I cannot absorb everything that is happening to me”. Fifty-seven individuals or 79.2% rarely to never felt as though they cannot absorb everything. Fifteen individuals or 20.9% felt it was hard to absorb everything that is happening sometimes to often. The fifty-fourth survey item asks, “It makes me angry when others try to help me”. Fifty-seven or 81.7% of the sample rarely to never felt angry when others try to help them. The fifty-fifth survey item asks, “I am interested in making plans for my future”. A large portion sixty-five individuals or 90.2% are sometimes to often interested in making plans for their future. Item number fifty-six asks, “It is difficult to keep my mind on one thing”. This

question showed wide variation. The largest portion of the sample, twenty-four individuals or 33.3% feel that it is sometimes hard to keep their mind on one thing. The final survey item number fifty-seven asks, "I can cope with almost all problems I face". Sixty-five respondents or 90.3% of the sample often to sometimes feel they can cope with almost all problems they face. This shows incredible resiliency and perseverance among individuals with CF.

Question #3 Do males and females with CF identify different psychosocial reactions to their disability as measured by the RIDI?

An Independent Groups T-Test statistic was used to examine differences between males and females and their responses on the RIDI. A summary of differences is shown in table 8. Significance is noted at the .05 level on the scale for shock. There are no other reactions that are significant at the .05 level, although depression is close at .06.

Table 8
Independent Samples Test measuring psychosocial reactions between males and females as measured by the RIDI.

Psychosocial Reaction		Levene's Test for Equality of Variances: F	Sig	Mean Difference	df	Sig. (2-tailed)
Shock	Equal variances assumed	6.281	.015	.3291	69	.011*
	Equal variances not assumed			.3291	54.485	.013
Anxiety	Equal variances assumed	3.660	.060	.1337	70	.127
	Equal variances not assumed			.1337	51.812	.139
Denial	Equal variances assumed	.141	.709	3.958E-02	70	.700
	Equal variances not assumed			3.958E-02	69.687	.697
Depression	Equal variances assumed	2.322	.132	.2186	70	.064
	Equal variances not assumed			.2186	58.125	.070
Internalized Anger	Equal variances assumed	3.450	.067	.1113	70	.390
	Equal variances not assumed			.1113	54.751	.402
Externalized Hostility	Equal variances assumed	.821	.368	.2129	70	.134
	Equal variances not assumed			.2129	63.995	.138
Acknowledgement	Equal variances assumed	.012	.915	.1154	70	.363
	Equal variances not assumed			.1154	69.900	.359
Adjustment	Equal variances assumed	2.165	.146	.1584	69	.287
	Equal variances not assumed			.1584	67.251	.282

* Note. $p < .05$, two-tailed

Question #4 Is there a correlation between the age of an individual with CF and the type of psychosocial reactions they exhibit as measured by the RIDI?

One-way analysis of variance (ANOVA) was used to examine the relationship between age and psychosocial reactions. Table 9 illustrates the ANOVA using each specific psychosocial reaction between males and females and significance at the .05 level is noted for the psychosocial reaction acknowledgement.

Table 9

One-Way Analysis of Variance measuring psychosocial reactions between age and psychosocial reactions as measured by the RIDI

Psychosocial Reaction		Sum of Squares	df	Mean Square	F	Sig
Shock	Between Groups	1.527	3	.509	1.725	.17
	Within Groups	19.776	67	.295		
	Total	21.303	70			
Anxiety	Between Groups	.112	3	3.738E-02	.264	.85
	Within Groups	9.623	68			
	Total	9.735	71	.142		
Denial	Between Groups	.999	3	.333	1.863	.14
	Within Groups	12.158	68	.179		
	Total	13.157	71			
Depression	Between Groups	.448	3	.149	.585	.63
	Within Groups	17.352	68	.255		
	Total	17.800	71			
Internalized Anger	Between Groups	1.214	3	.405	1.391	.25
	Within Groups	19.771	68	.291		
	Total	20.984	71			
Externalized Hostility	Between Groups	1.005	3	.335	.928	.43
	Within Groups	24.535	68	.361		
	Total	25.540	71			
Acknowledgement	Between Groups	2.359	3	.786	2.991	.04*
	Within Groups	17.876	68	.263		
	Total	20.235	71			
Adjustment	Between Groups	1.303	3	.434	1.128	.34
	Within Groups	25.804	67	.385		
	Total	27.107	70			

* Note. $p < .05$, two-tailed

Question #5 Do individuals with CF who have siblings with CF and individuals with CF that do not have siblings with CF show significant differences to reactions as measured by the RIDI?

An Independent Groups T-Test statistic was used to determine if individuals with CF who have siblings with CF and individuals with CF who do not have siblings with CF show significant reactions. No significant differences were found among groups. Table 10 shows that there was no significance found using the Independent Samples T-Test.

Table 10

Differences between individuals who have siblings with CF and siblings without CF.

Psychosocial Reaction		F	Sig	Mean Difference	df	Sig. (2-tailed)
Shock	Equal variances assumed	.210	.648	.1162	69	.416
	Equal variances not assumed			.1162	45.003	.397
Anxiety	Equal variances assumed	.164	.687	5.173E-02	70	.589
	Equal variances not assumed			5.173E-02	50.657	.553
Depression	Equal variances assumed	.000	.986	9.195E-02	70	.477
	Equal variances not assumed			9.195E-02	44.305	.460
Internalized Anger	Equal variances assumed	.700	.406	.2111	70	.130
	Equal variances not assumed			.2111	41.076	.130
Externalized Hostility	Equal variances assumed	.360	.551	.1669	70	.280
	Equal variances not assumed			.1669	39.893	.284
Acknowledgement	Equal variances assumed	1.636	.205	8.883E-02	70	.519
	Equal variances not assumed			8.883E-02	58.728	.453
Adjustment	Equal variances assumed	1.759	.189	-5.4665E-02	69	.735
	Equal variances not assumed			-5.4665E-02	54.893	.702

Question #6 Does the relationship with siblings affect RIDI scores?

An Independent Groups T-Test was used to examine differences among sibling relationships and psychosocial reactions to CF. Levene's Test for Equality of Variances was used to equate differences in-group size. Significant differences were noted on the adjustment subscale, at the .01 level. A summary of group reactions is listed in table 11.

Table 11
Independent Samples T-Test measuring sibling relationships and their affect on RIDI scores.

Psychosocial Reaction		F	Sig	Mean Differences	df	Sig. (2-tailed)
Shock	Equal variances assumed	6.760	.011	-.2937	67	.077
	Equal variances not assumed			-2.937	15.041	.219
Anxiety	Equal variances assumed	6.093	.016	-.1455	68	.196
	Equal variances not assumed			-.1455	14.912	.374
Denial	Equal variances assumed	5.141	.027	-4.3367E-02	68	.737
	Equal variances not assumed			-4.3367E-02	17.118	.776
Depression	Equal variances assumed	4.722	.033	-7.6212E-02	68	.615
	Equal variances not assumed			-7.6212E-02	15.195	.718
Internalized Anger	Equal variances assumed	4.072	.048	-.2612	68	.111
	Equal variances not assumed			-.2612	15.202	.258
Externalized Hostility	Equal variances assumed	4.864	.031	-.3231	68	.074
	Equal variances not assumed			-.3231	15.848	.178
Acknowledgement	Equal variances assumed	.004	.949	.2474	68	.127
	Equal variances not assumed			.2474	18.781	.161
Adjustment	Equal variances assumed	2.109	.151	.4874	67	.008*
	Equal variances not assumed			.4874	16.910	.034

* Note. $p < .01$, two-tailed

The following questions were asked at the end of the survey, to gain additional insight into how CF impacts the lives of adolescents and young adults.

Looking at whether individuals with CF have someone to confide in, a large number of respondents 89.9% (n=62) indicated that they did have someone to confide in about their CF. It is alarming to note that 10.1% (n=7) of the sample did not have someone they can confide in. Looking at the relationship that individuals have with their confidante, a large portion of individuals responded with multiple responses (36.1%) including teachers, girlfriends, boyfriends, fiancé, doctor, Jesus, and wife. Friends 24.6% (n=15) and parents 18.0% (n=11) rounded out the most frequent relationships. Individuals were also asked if they felt that their family life revolved around cystic fibrosis. Nearly 80% felt that their family life does not revolve around their disability.

Participants were asked about the length and quality of their care at the University of Minnesota Hospital and Clinic. It was found that 79.2% (n=57) of the sample has been attending the U of M for 8 or more years. Eight individuals or 11.1% have just started coming to the U of M within the last 2 years. Another question asked about their satisfaction with the CF care team. The vast majority of respondents 97.2% (n=69) were satisfied with their relationship with their medical team. A follow-up question asked participants if there was anything they could do to improve services on the part of the CF care team. Again, an overwhelming number of respondents 86.4% (n=57) felt that there is nothing that

their CF care team can do to improve. The next question looked at the amount of physical therapies performed a day. Half the sample 50% (n=36) said that they do 2 therapies a day, with 95.8% (n=69) performing within 1 to 3 therapies a day. Participants were also asked whether they felt they had to hide their medications. It was found that nearly a quarter of the sample 22.5% (n=16) felt that they have to hide their medications around other people.

Finally, participants were asked questions about their physical stature and engagement in activities. The next question asked whether individuals with CF are satisfied with their physical stature. Nearly 24% of the sample 23.9% (n=17) indicated that they were not satisfied with their physical stature. The final question asked about participation in sports. A high number of the respondents 72.2% (n=52) participate in sporting events. Approximately 1 in 4 respondents stated that they do not participate in any sports. This is alarming due to the fact that the medical profession encourages individuals with CF to get a large amount of exercise.

CHAPTER V: CONCLUSIONS AND RECOMMENDATIONS

Introduction

The psychosocial aspects of Cystic Fibrosis in teenagers and young adults were examined. Based on responses from the survey instrument "Reactions to Impairment and Disability Inventory", respondents were evaluated on a number of subscales (shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement, and adjustment). In addition to this survey, respondents were asked to answer a series of questions in regards to their own personal experience with CF. Conclusions and recommendations will be reached based on results from this study.

Summary of Findings

Results from this study show significance between males and females and their reactions to their disability as measured by the RIDI. Statistical significance was noted at the .05 level for the subscale of shock. Shock is defined as the individuals' initial or emergency reaction to the onset of a sudden injury or diagnosis of a terminal chronic illness. The individual must gather their energies to combat the initial overwhelming or painful stimuli. Females responded with a higher average for shock as compared with males. Possible reasons as to why females would experience greater levels of shock than males could include females are traditionally seen in society as more emotional and more in tuned with their emotions than males. Being in tuned with these emotions could explain

why females would tend to dwell on the long-term ramifications of the illness. It is interesting to note that females with CF according to statistics do not survive as long as males with the disability. Once females digest that they have this disability they may find out that the life expectancy is even worse for females. They may not be able to handle the overwhelming psychological pain and resort to higher levels of shock. Looking at the subscale of depression, females responded with a much higher average than males. The same reasons as above could explain why females would be more depressed than males. Females in our society are forced to be interested in how they look physically. Females may be worried on how this terminal illness will affect their overall appearance. Females also scored substantially higher on the scale of externalized hostility. Externalized hostility occurs when an individual attempts to retaliate against the functional limitations of the perceived threat. The hostility is usually directed at people, objects or the environment. Why would females average higher scores than males? Males have always been seen as risk takers and are more aggressive. Whether you are a male or female, bottling up negative emotions about the illness, will inevitably lead to externalized outbursts of emotions toward others or objects. It is interesting to note that females averaged higher than males in all the subscales. Looking at the positive subscales of acknowledgement and adjustment, females scored higher averages than males. This means that females realized that they do have an impairment, and are learning to adjust to the new

functional limitations that comes with a diagnosis of terminal chronic illness. Males scored not as high as females but still scored quite well on acknowledgement and adjustment. The terminality of CF causes individuals to acknowledge and adjust to their illness quickly or they will be subject to rapid deterioration and hospitalization leading ultimately to death.

One research question looked at whether individuals with CF who have siblings with CF or siblings without CF and how that may have affected the RIDI scores. Twenty-two of the seventy-two respondents who participated in this survey have siblings with CF. Individuals who have siblings with CF showed higher averages in six of the eight subscales (shock, anxiety, depression, internalized-anger, externalized hostility, and acknowledgement). Possible reasons why individuals who have siblings with CF would score higher on the subscales than individuals who do not have a sibling with CF could be that they feel angry in the fact that their sibling would also have CF. They may feel depressed that their sibling would have to go through what they have been through with CF. This would be more apparent with siblings who are older and separated by a number of years. Older siblings would recall all the things they went through with their illness and be depressed that their brother or sister would have to go through the same things. The lack of control over the situation could lead to internalized anger or externalized hostility.

Respondents who have a good relationship with their siblings showed an overall lower average for anxiety, shock, denial, depression, internalized anger, externalized hostility and a higher average for acknowledgement and adjustment. Having someone you can confide in about CF can have a significant impact. A sibling that has been through the trenches can offer advice and support to a sibling who is about to go through the progression of CF. Significance was noted for the subscale of adjustment. Adjustment is the theoretical last phase of the adaptation process of disability. The individual assimilates the functional limitations of the illness and creates a new self.

Having someone to can talk to about CF who is going through or has gone through the same problems you are can help buffer negative emotions. Having a good relationship with siblings provides an individual with someone they can confide in.

The final portion of the survey looked at a number of questions pertaining to an individual's own personal experience with CF. Individuals with CF as a whole spend a great deal of time doing their physical therapies. Physical therapies are essential to maintaining healthy lungs by allowing for mucus to be expelled. It takes an intense time commitment to do physical therapies. If you add the schedule of school, extra-curricular activities and free time you don't have a lot of time for therapies. Approximately 96% of the sample tried to do at least 1

to 3 therapies a day. This shows that these individuals are making the time and effort to stay as healthy as they can.

Nearly all individuals with CF are required to take oral medications. Approximately 1 in 4 respondents say that they feel they need to hide their medications. When you are at school, you want to fit in and be as "normal" as the other kids. When you have to take 10 or more pills at every meal, it can be a major distraction. It draws attention to an individual that may cause undue hardship.

Conclusions

As an individual with CF gets older, it appears that they exhibit less negative emotions of shock, anxiety, denial, depression, internalized anger, externalized hostility, and more positive emotions of acknowledgement and adjustment. Significance was noted at the .05 for the subscale of acknowledgement. That means that as an individual with CF grows older, they are better able to acknowledge and accept their disability. When an individual is younger they must deal with the incredible amount of responsibility to take care of themselves. Hours of physical therapy, medications, and the demanding regimen can be overwhelming. If you add this intense schedule along with the responsibilities of school and this can be a very challenging time. As an individual grows older, they mature and realize the significance of doing physical therapies, taking medication and exercise. It is interesting to note that the age

group of 22 and older had the lowest mean for all the negative subscales and the highest mean for acknowledgement and adjustment.

During the school years, many individuals are interested in looks and appearance. Individuals who are smaller and underweight can be susceptible to bullying and being pushed around. Approximately 24% of this sample said that they were unsatisfied with their physical stature. It is interesting to note that the individuals that were unsatisfied were split 50-50 among males and females. Males have an incredible amount of pressure to live up to the ideal male, strong, tall, and muscular, while females have to live up to the ideal woman who is skinny, and attractive. A focus needs to help adolescents accept their bodies and be proud of them.

Participation in sports is of prime importance during the adolescent years. Exercise provides the individual with CF a way to clear their airways and strengthen their lungs. Exercise contributes better overall physical health and psychological health. An alarming 28% of this sample said they do not participate in any sports. It should be highly encouraged to participate in some form of physical activity. It should be noted

those individuals might have interpreted participating in sports as being on a high school sport team, when some individuals may exercise while not being on a sporting team.

Having someone to confide in about things in your life is very important. Confidantes can help buffer life stressors and provide you with someone to bounce your thoughts off of. When someone feels they do not have someone they can confide in, it can lead to emotions being kept inside and a feeling of hopelessness. Ten percent of this sample felt that they did not have anyone they could confide in. Growing up is hard enough on someone who is healthy, but the addition of having a life threatening illness and it can be frightening. A majority of the respondents felt that they could confide in a friend or their parents. It was very interesting to note that confiding in siblings was not as high as friend or parent. Why would an individual not want to confide in their sibling? They might feel that their relationship with their sibling is not as good as their relationship with their parents and friends. Another reason could be that there is a wide age difference between them or they are closer with their friends and feel that their siblings wouldn't understand what they were going through. This researcher found this to be very puzzling considering 22 of the 72 participants had siblings with CF.

Recommendations

If this study were to be replicated, there are a number of things that this researcher would like to investigate. The first addition would be to ask along with how many therapies a day, the amount of time spent on each therapy. This would illustrate the time restraints required to maintain one's health and provide the

reader with an idea of how much actual time is needed for physical therapies. In examining whether individuals with CF are satisfied with their physical stature, it would be important to distinguish if un-satisfaction was due to CF, or just how an individual feels about himself or herself. Un-satisfaction may have to deal with growing pains all adolescents face and not just those with CF. The question, participation in sports, it would be beneficial to reword this question to "do you participate in any physical activity". This would include individuals who participate in high school sports and also individuals who exercise for fun.

When looking at family life and if it revolves around CF, it would be more informational to find out what aspects of CF revolve around family life. Finding out if there is significance between RIDI scores and physical therapies a day, physical stature, and participation in sports may be informational. Finally, having a control group would allow the researcher to compare with a healthy control and examine the differences between individuals with CF and a healthy control.

Individuals as a whole showed very positive responses to a majority of this survey. Individuals with CF acknowledge they have a disability and as they get older learn to adjust to the demands of CF. The overall positive attitude of individuals with CF is illustrated with questions such as "I am satisfied with my present abilities despite my impairment", "Although restricted, there is much I can do", "Living through CF, I understand things better", "When I look in the mirror I see myself and not a disability", "I am interested in getting socially

involved with others", "I realize my impairment is a part of me, but I don't let it interfere with my life", "I am interested in making plans for my future", "I can cope with almost all problems I face," "I am interested in forming new relationships", and "Despite my impairment, I can do most things that non-impaired people can do". Individuals in this sample were very positive about living with CF. Recommendations for individuals who take care of Cystic Fibrosis whether that be the doctor, nurse, psychologist, pharmacist need to take care of the body as well as the mind. A positive attitude toward CF can only encourage better overall health. The biggest areas of concern that should be addressed if additional research is to be conducted include participation in exercise, and medication compliance. Along with physical therapies, exercise is an invaluable tool in fighting CF. Embarrassment from taking medications can be lessened by teaching adolescents ways to be secretive about taking their medications. Learning ways to be less obvious can alleviate problems with medications.

A related area that needs to be addressed is attitudes about one's own body. CF imposes a heavy toll on the body of someone with CF and to find ways to combat negative thinking is a challenge. The school years, especially peer relations, can be made difficult with someone who is smaller and underweight due to CF.

Individuals with CF are living a lot longer than even 5 years ago. Technology has allowed for those with CF to maintain a somewhat normal lifestyle. Adolescents with CF should be encouraged to seek long-term employment goals and the field of rehabilitation has to be ready for these individuals by having the necessary knowledge to guide them through the employment process.

A final area that should be addressed is providing those with CF who feel they do not have someone to confide in a lifeline. Living with a life-threatening illness requires that you have someone you can talk to about life's difficulties. CF care teams should be encouraged to reach out to those that do not have the support they need, and provide information and referral to support systems outside of the health care facility.

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Appendix A

Script for Laboratory Technicians

Step 1: Participants will arrive to the Cystic Fibrosis clinic and report to the Pulmonary Function laboratory.

Step 2: Laboratory Technicians (Ione Brown/Ann Hazzelwood) will ask participants if they would like to participate in a research study about the psychological and social aspects of Cystic Fibrosis.

Step 3: If subjects are willing to participate, the lab technicians will give them a copy of my introduction. (See attached)

Step 4: Once the subject has read through the introduction, the lab technicians will provide the assent form to the young adult, and the consent form to the parents.

Step 5: The lab technicians address any specific questions regarding these materials. (Note: lab technicians will have received prior training regarding common questions and concerns)

Step 6: Next, the laboratory technicians will give the subject a copy of the Reactions to Impairment and Cystic Fibrosis Inventory and a sheet that asks demographic information.

Step7: When this is completed subjects will fold their survey and demographic information into an envelope and seal it and place it directly in the locked "survey return box". Alternately, they may give the sealed envelope to the lab technician to deposit.

Step 8: The technicians will give the subjects the "thank you for participating" letter and this will mark the conclusion of the study.

Appendix B

THE PSYCHOSOCIAL ASPECTS OF TEENAGERS AND YOUNG ADULTS WITH CYSTIC FIBROSIS

We are asking if you are willing to fill out questions about Cystic Fibrosis. We are trying to understand how Cystic Fibrosis has an effect on lots of areas in your life and how you feel about it. CF can be tough to deal with and we hope that we can identify what it is about CF that is difficult.

If you agree to be in this study, we will ask that when you come to your appointment at the CF clinic you answer some questions. The list of questions is called a survey. During your visit to the clinic you are required to do some blowing tests on your lungs. While you are waiting to do these tests, the lab technician will give you the survey to fill out. When you have completed it, the survey will be placed in a sealed envelope and then placed in a locked box. You do not have to worry about anyone in the CF clinic looking at it, your responses are private and there will be no way for anyone to know what you have put down.

If you change your mind about answering the questions, you can always stop at any time. Your participation in this study is totally up to you, and no one will be mad at you if you don't want to do it. You can ask any questions that you have about this study. If you have a question later that you didn't think of now, you can ask us next time.

Remember, being in this study is up to you, and no one will be mad at you if you don't want to participate or even if you change your mind later. By completing this survey you agree to participate in this study.

Appendix C

THE PSYCHOSOCIAL ASPECTS OF TEENAGERS AND YOUNG ADULTS WITH CYSTIC FIBROSIS

My name is Christopher Tolbert. I am a graduate student at the University of Wisconsin-Stout in the Vocational Rehabilitation program, and am requesting your assistance in gathering information about Cystic Fibrosis. Cystic Fibrosis has been shown to have a tremendous impact in areas like school, strict therapy regimens, economic pressures, a constant vigilance to avoid sickness, a loss of sense of control, uncertainty of health status, peer relations, independence, daily regimens, sports, family life, medical community and self perception. The goal of this study is to understand the psychosocial areas that affect individuals with Cystic Fibrosis. Once identified, these issues can help enlighten the Cystic Fibrosis care team to better address areas of concern for teenagers and young adults with Cystic Fibrosis. Advances in technology have allowed individuals with Cystic Fibrosis to live longer. With this longer life expectancy, new issues are arising and a detailed look at psychosocial functioning is needed. The primary objectives of this study are to understand how Cystic Fibrosis impacts all areas of an adolescent's and young adult's life, their level of self-esteem, the emotional aspects of having Cystic Fibrosis, the reality of living with Cystic Fibrosis, and the interaction with others who do not have Cystic Fibrosis.

Your participation is strictly voluntary and will require around 10 minutes of your time. If you are willing to participate in this study, please read the attached consent form. You may keep one copy for yourself; the researcher will keep the other. You will be asked to complete a 57-question survey about your experience with living with Cystic Fibrosis. The survey will ask you to rate on a scale of "never occurring" to "occurring often" about a variety of social and emotional factors. Information will be coded to protect your identity. If you wish

to have access to a summary of this study and the information gathered or to even ask questions, you may use the contact information available on the consent form. A full report of this research, including results and recommendations for future research will be submitted to the hospital and will be made available for your review.

CONSENT FORM

Your child has been invited to participate in a research study. The purpose of this study is to identify how Cystic Fibrosis affects numerous areas of your child's life. Before deciding whether your child should complete this survey, please read the following information and then consider allowing them to participate. It is important that you understand the possible risks and benefits of participation, and that you understand the rights of your child.

RISKS & BENEFITS

As with any research, there are some risks to participation. There is minimal risk to your child in completing this survey. When answering some of the questions on this survey, they may experience some anxiety or discomfort. Although all information is confidential, your child is not required to answer any questions that make them feel uncomfortable, and they may choose to stop at any time. Although the results of this study may benefit others in the future, there is no direct benefit to your child by participating in this study. It is hoped that the results of this research will bring attention to the social and emotional aspects of Cystic Fibrosis that are just as tough as the physical aspects of the disease. Although it is unlikely, if your child experiences any lasting discomfort or has concerns about the survey, you may wish to consult a medical or counseling professional. Please contact the primary researcher so that you may be given information regarding recommended professionals to contact. Contact information is included below.

CONFIDENTIALITY OF RESPONSES

The answers that your child provides will be strictly confidential. Only the primary researcher and research advisor will have access to this information. According to federal regulations, the results must be saved for at least 5 years. Information will be protected and will remain in a locked location within the Cystic Fibrosis clinic. Access will be limited to the primary researcher and research advisor throughout this time.

RIGHT TO WITHDRAW OR DECLINE TO PARTICIPATE

Your child's participation in this study is strictly voluntary. They may choose not to participate without any negative consequences to them. If they choose to participate and later wish to withdraw from the study, they may discontinue at any time without affecting your family's current or future relations with the clinic. By allowing your child to complete the survey, it is assumed that you have read and understood the above descriptions, including possible risks, benefits, and your child's rights as a participant, and that all of your questions about the study have been answered to your satisfaction. By your child completing this survey they agree to participate in this study

NOTE: Questions or concerns about the research study should be addressed to Christopher Tolbert, the primary researcher at: tolbertc@post.uwstout.edu or (715) 339-2818 or the research advisor Dr. Kathleen Deery at deeryk@uwstout.edu or (715) 232-2233. You may also contact Sue Foxwell, Human Subjects Protections Administrator, UW-Stout Institutional Review Board for the Protection of Human Subjects in Research, 11 Harvey Hall, Menomonie, WI. 54751 phone (715) 232-1126.

Appendix D

Reactions to Impairment and CF Inventory

The following survey has a list of possible reactions to Cystic Fibrosis. Please circle the appropriate number to the right of each question that indicates to what extent you are experiencing each specific reaction to your disability. There are no "right" or "wrong" answers. The degree to which you truly experience each reaction, as expressed by the statements, should be your answer. Please respond to all the statements on the inventory as honestly as possible. The information you provide will remain completely anonymous.

1	=	**Never**	Reaction is never experienced
2	=	**Rarely**	Reaction is seldom experienced, 1 to 4 times per month
3	=	**Sometimes**	Reaction is occasionally experienced, 5 to 10 times per month
4	=	**Often**	Reaction is frequently experienced, 10 or more times per month

1.	Having Cystic Fibrosis has made me less interested in other people.	1 2 3 4
2.	If I become a better person, my disease will be cured.	1 2 3 4
3.	As my disease has progressed, I cry more often than I used to.	1 2 3 4
4.	When I look back on what has happened to me, I feel bitter.	1 2 3 4
5.	God will cure me, if I improve my behavior and follow his ways.	1 2 3 4
6.	I am a failure as a person.	1 2 3 4
7.	I am satisfied with my present abilities despite my physical impairment	1 2 3 4
8.	As my disease has progressed, I have attacks of panic.	1 2 3 4
9.	My disease must be a punishment for something I did in the past.	1 2 3 4
10.	I am embarrassed about having Cystic Fibrosis.	1 2 3 4
11.	There are more important things in life than those that my disease prevents me from doing.	1 2 3 4

12.	I have difficulty finding a reason to get up in the morning.	1 2 3 4
13.	If I were a nicer person, I would regain my abilities.	1 2 3 4
14.	I am rearranging some of my life priorities.	1 2 3 4
15.	Although I am restricted in certain ways, there is still much I am able to do.	1 2 3 4
16.	My life is empty.	1 2 3 4
17.	I find myself trembling without any apparent reason.	1 2 3 4
18.	It makes my blood boil to have somebody talk about my disease.	1 2 3 4
19.	Living through Cystic Fibrosis, I feel that I understand things better.	1 2 3 4
20.	I feel nothing will ever be the same again.	1 2 3 4
21.	I am certain that I will be completely cured.	1 2 3 4
22.	When I look at other people, I am eaten up with jealousy.	1 2 3 4
23.	I am so restless that I cannot sit still.	1 2 3 4
24.	Nobody is going to tell me what to do.	1 2 3 4
25.	I get mad enough to smash things.	1 2 3 4
26.	When I look in the mirror, I see myself and not a disability.	1 2 3 4
27.	My mind goes blank.	1 2 3 4
28.	I feel lonely even when with friends.	1 2 3 4
29.	Everything in my life is coming together again.	1 2 3 4
30.	I blame myself for what happened to me.	1 2 3 4
31.	I find myself asking: “Why did this happen to me?”	1 2 3 4

32.	I feel frozen, unable to move.	1 2 3 4
33.	I am seeking new meaning for my life.	1 2 3 4
34.	I am interested in getting socially involved with other people.	1 2 3 4
35.	I feel that there is nothing I can do to help myself.	1 2 3 4
36.	I cannot believe that this is happening to me.	1 2 3 4
37.	I got a raw deal out of life.	1 2 3 4
38.	I do not mind accepting help when I need it.	1 2 3 4
39.	I will soon be just as I was before.	1 2 3 4
40.	As my disease progresses, I have had periods when my heart pounds.	1 2 3 4
41.	I think that it is all a nightmare from which I will soon awaken.	1 2 3 4
42.	I am impatient with the medical treatment recommended for me.	1 2 3 4
43.	I realize that my physical impairment is part of me, but I do not let it interfere with my life.	1 2 3 4
44.	I feel like getting even with someone.	1 2 3 4
45.	I feel like screaming at others.	1 2 3 4
46.	I feel confused about what is happening to me.	1 2 3 4
47.	I believe that nothing is wrong with me.	1 2 3 4
48.	I am interested in forming new friendships.	1 2 3 4
49.	I believe that my disease will go away by itself.	1 2 3 4
50.	Having Cystic Fibrosis has caused me to have nightmares.	1 2 3 4

51.	I find myself arguing more with people.	1	2	3	4
52.	Despite my physical impairment, I can do most things non-impaired people can do.	1	2	3	4
53.	I cannot absorb everything that is happening to me.	1	2	3	4
54.	It makes me angry when people try to help me or do things for me.	1	2	3	4
55.	I am interested in making plans for my future.	1	2	3	4
56.	It is difficult to keep my mind on one thing.	1	2	3	4
57.	I can cope with almost all problems I face.	1	2	3	4

* Adapted from Hanoch Livneh and Richard Antonack 1989

Appendix E

PLEASE PROVIDE THE FOLLOWING DEMOGRAPHIC INFORMATION FOR DATA ANALYSIS PURPOSES. YOUR RESPONSES WILL REMAIN COMPLETELY ANONYMOUS. THANK YOU.

1. **Gender: Female_____ Male_____**
2. **Age: 13-15_____ 16-18_____ 19-21_____ Over 22_____**
3. **Marital status: Single___ Married___ Separated___ Divorced___ Widowed___**
4. **Highest grade completed: _____example: Freshman = 9,**

   Sophomore = 10 etc.
5. **Do you have any siblings? Yes or No _____**
   a. **If Yes what age(s)**
      _____
6. **Do any of your siblings have Cystic Fibrosis? Yes or No _____**
   a. **If Yes what age(s)**
      _____
7. **How long have you been coming to the University of Minnesota Hospital and**

   Clinic?

   0-2 years _____ 3-5 years _____ 6-7 years_____ 8 years or longer_____
8. **How many physical therapies (bd's) do you do a day?**

   0___ 1___ 2___ 3___ 4 or More ___

9. Do you feel like you need to hide your medications when you take them?

Yes ___ No___

Comments (optional):

_____
_____
_____
_____

10. Are you satisfied with your physical stature? Yes___ No___

a. If No, what would you like to change?

_____
_____
_____
_____
_____

11. Do you participate in any sports? Yes ___ No___

a. If Yes, which ones? _____

12. Do you feel that your family life revolves around Cystic Fibrosis?

Yes ___ No___

Comments (optional):

_____
_____
_____
_____

13. How would you rate your relationship with your siblings?

Good ___ Fair___ Poor___

Comments (optional):

_____

_____
_____
_____

14. Do you have a special person that you can confide in about your

Cystic

Fibrosis who you feel understands your needs?

Yes ___ No___

a. If Yes, what is your relationship to that person?

Parent _____Sibling _____ Friend _____ Teacher _____

Other (specify)
_____

15. Are you satisfied with your relationship with your Cystic Fibrosis care team?

Yes ___ No___

Comments (optional):
_____
_____
_____
___

16. Is there anything you feel the Cystic Fibrosis care team can do to improve your relationship with them?

Yes ___ No___

Comments (optional):
_____
_____

THANK YOU FOR YOUR COOPERATION IN RESPONDING TO THIS QUESTIONNAIRE

Appendix F

Thank you for Participating

Thank you for participating in this study. Now that you've completed the questionnaire, I would like to tell you a little about myself and my motivation for conducting this research. My name is Christopher Tolbert and I was born with Cystic Fibrosis. My brother who is 17 also has Cystic Fibrosis. Over the years, we visited many doctors around Wisconsin, but settled at the University of Minnesota and have been coming here for more than 10 years. After graduating from high school, I attended the University of Wisconsin-Stout, and graduated in 2000 with a bachelor's degree in Psychology. I decided to go on for more school and chose the field of Vocational Rehabilitation, which is helping those with disabilities get back into the world of work. I am in now my final year of graduate school at the University of Wisconsin-Stout. One of the requirements for graduation includes completing a research study. I wanted to do research on Cystic Fibrosis because I felt that doctors need to focus more on how patients are feeling, not just on the physical aspects of CF. In my experience, I had a lot of problems growing up with CF. It was a really tough time, and I received very little support when it came to my feelings and self-esteem. I believe that this study will enlighten individuals who work with people with CF about how it affects all areas of a person's life.

If you have any questions or concerns about the research study please feel free to contact me by email at tolbertc@post.uwstout.edu or by phone at (715) 339-2818.
If you feel like this survey has caused you any psychological distress or you need to talk to someone you may also contact my research advisor Dr. Kathleen Deery at deeryk@uwstout.edu or (715) 232-2233. You may also contact Sue Foxwell, Human Subjects Protections Administrator, UW-Stout Institutional Review Board for the Protection of Human Subjects in Research, 11 Harvey Hall, Menomonie, WI. 54751 phone (715) 232-1126.