

THE RELATIONSHIP OF PARENTAL OVERPROTECTION
AND PARENTING STRESS TO PSYCHOLOGICAL
DISTRESS IN PARENTS OF CHILDREN WITH
ASTHMA AND CYSTIC FIBROSIS:
A CROSS ILLNESS COMPARISON

By

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CHAPTER I

INTRODUCTION

Asthma is the most common chronic illness of childhood, often resulting in significant limitations in children's daily activities. It is estimated that 6.3 million children under 18 years of age have asthma, of which 4 million suffered an asthma attack or episode in the past year (American Lung Association, 2003). The asthma hospitalization rate has grown by 1.4 % per year from 1980 to 1999. Although childhood asthma deaths are rare, the asthma death rate increased by 3.4% per year from 1980 to 1998. After reaching a peak of 3.8 per 1 million children in 1996, the childhood asthma death rate declined 18% in 1997 to 3.1 per 1 million. However, asthma mortality rose again in 1998 to 3.5 per 1 million (Akinbami & Schoendorf, 2002).

Cystic fibrosis (CF) is also a pulmonary illness, yet it is characterized as invariably more progressive and fatal in nature than asthma. The prognosis for children with CF has improved remarkably in the last two decades with improvements in the diagnosis and treatment of this disease, including use of physiotherapy, digestive enzymes, antibiotics and nutritional approaches (Willis, Miller, & Wyn, 2001). The median life expectancy of children with cystic fibrosis born in 1990 is now estimated to be 40 years, double that of 20 years ago (Elborn, Shale, & Britton, 1992; Kulich, Rosenfeld, Goss, & Wilmott, 2003). Although there have been advances in disease

management, a normal life expectancy has not yet been achieved for these children (Derouin & Jessee, 1996).

Inevitably, parents of children with asthma and CF encounter considerable disease-related demands, uncertainty, and stress, which ultimately impinge on their adjustment. Such issues have been well documented in the literature (e.g., Holmbeck et al., 2002; Livneh & Antonak, 1997; Thompson, Gil, Burbach, Keith, & Kinney, 1993; Thompson & Gustafson, 1996). Research has demonstrated that families of school-aged children with asthma experience high levels of stress (Bursch, Schwankovsky, Gilbert, & Zieger, 1999; Bussing & Burkett, 1993; Gartland & Day, 1999), often greater than either families with healthy children or families of children with other chronic illnesses (Svavarsdottir, McCubbin, & Kane, 2000). Parents of children with asthma also face stress due to coping with a child's chronic illness, as well as typical stressors associated with parenting. Mothers of children with CF are often reported to experience greater stress and poorer adjustment than mothers of well children or compared to population norms (Foster, Eisner, & Oades, 2001). They also face the demands associated with parenting a child, regardless of the child's health status. Therefore, parenting stress as well as global psychological distress may contribute to the development of dysfunctional parent-child relationships (Abidin, 1995; Deater-Deckard, 1998).

Notably, a relatively unexplored area in the literature concerns how specific parental psychological variables, such as parental overprotection and parenting stress, are associated with psychological distress in different illness groups (Thomasgard, 1998). Parental overprotection is one variable that is potentially associated with the psychological functioning in parents of chronically ill children. Overprotective parents

may be described as being highly vigilant, having difficulty with separation, exercising a high level of control, and discouraging independent behavior. According to Holmbeck et al. (2002), parental overprotection may serve an adaptive function, as parents attempt to maintain the health of their child and regulate their own exposure to stress. Indeed, research has demonstrated that children with asthma are often not allowed to participate in typical childhood activities enjoyed by their non-asthmatic peers (Young & Roopnarine, 1994). However, excessive overprotection may also lead to negative consequences, leading to parent-child conflict and the development of behavior problems in the child (Holmbeck et al., 2002; Thomasgard, 1998; Thomasgard & Metz, 1997; Thompson & Gustafson, 1996).

Parenting stress is another variable associated with psychological distress. Parenting stress can be defined as the stress that is associated with parenting a child. Research has shown that mothers of children with chronic illnesses may be more susceptible to stress and psychological distress secondary to the demands of the disease (Thompson, 1986; Wallander, 1993). Connections between parental distress, parenting stress, and parenting styles on a child's cognitive and social development have been proposed (Livneh & Antonak, 1997). Parenting stress has also been associated with poor maternal psychological adjustment, perceived loss of control, less than optimal parenting, higher levels of family conflict, and poorer family functioning outcomes (Asencio, 2003; Macias, Clifford, & Saylor, 2001; McMahon, Gibson, & Leslie, 2003; Streisand, Kazak, & Tercyak, 2003). A recent investigation by Mullins, Fuemmeler, & Hoff (2004) revealed that parenting stress was associated with higher levels of depressive symptoms in 8- to 12-year-old children diagnosed with Type 1 Diabetes

Mellitus (DM1). Further, parenting stress appeared to magnify the relationship between perceived child vulnerability and child-reported depressive symptoms. Clearly, parenting stress may have negative effects not only for the parent, but for the family and child as well.

The current study is aimed at determining the relationships between parental overprotection, parenting stress, and psychological distress in parents of children with asthma and parents of children with CF. Differences in parenting variables both between and within asthma and CF groups are of particular interest. Specifically, this research will address the following questions:

1. Do mean levels of parental overprotection, parenting stress, and psychological distress differ in mothers of children with CF compared to mothers of children with asthma?
2. Do parental overprotection and parenting stress have independent effects on psychological distress?
3. Will differential correlational relationships exist between parental overprotection, parenting stress, and psychological distress within the two illness group?

It is hypothesized that:

1. Higher mean levels of parental overprotection, parenting stress, and psychological distress will be found in mothers of children with CF compared to mothers of children with asthma.
2. Parental overprotection will be significantly related to psychological distress within each illness group.

3. Parenting stress will be significantly related to psychological distress within each illness group.
4. Differential correlational relationships will exist between parental overprotection, parenting stress, and psychological distress within the two illness groups.

For exploratory reasons, the following research question will be posed:

1. What are the independent contributions of parental overprotection, parenting stress, illness parameters, and demographic parameters to psychological distress within the combined group?

The study will begin with a brief description of each illness, including incidence and prevalence, severity, treatment methods, and outcomes. Thereafter, literature on psychological factors associated with asthma and CF will be discussed. This will include a description of the psychological stressors that parents of children with asthma and parents of children with CF experience. The constructs of parental overprotection and parenting stress will then be discussed, and literature regarding these variables will be reviewed. The hypothesized relationships between the variables will then be set forth.

CHAPTER II
LITERATURE REVIEW

Asthma

Description of the Illness

Childhood asthma is a chronic respiratory disorder characterized by recurrent episodes of airway obstruction and dyspnea (i.e., breathlessness) (Rietveld, Prins, & Colland, 2001). Individuals with asthma experience reversible airway obstruction, airway inflammation, and increased airway responsiveness to a variety of stimuli (Schulz, Dye, & Jolicoeur, 1994). According to Young and Roopnarine (1994), presenting symptoms are mainly wheezing and dyspnea if the reaction primarily involves the smaller airways. If the reaction involves the large to mid-sized bronchi, bronchial irritation results in a cough being the predominant symptom. The hallmark feature of asthma is its extreme variability, characterized by an intermittent, unpredictable, and reversible disease course (Chaney, Mullins, & Uretsky, 1999). This feature has several implications for the child's psychological and psychosocial functioning. Further, the clinical presentation of asthma is widely variable both across patients and within the same patient over time (Chaney et al., 1999). Thus, despite advances in medical treatments, asthma continues to be an extremely challenging and potentially life-threatening illness (Weitzman, Gortmaker, Sobol, & Perrin, 1992).

Incidence and Prevalence

Asthma is the most common chronic illness of childhood, afflicting millions of American children. According to the American Lung Association (March, 2002), it is estimated that 24.7 million people have been diagnosed with asthma by a health professional; more than a third of them (at least 7.7 million) are children under 18 years of age. In 1999, 3.8 million (out of the 7.7 million) of these individuals had an asthma episode. Asthma incidence, severity, and mortality have demonstrated substantial increases over the past two decades (Weiss & Wegener, 1990). Incidence rates increased approximately 75% between 1980 and 1994 across all age, race, and gender groups (MMWR, 1998).

Severity

Asthma is classified based on the severity, frequency and duration of symptoms, the degree to which airflow is obstructed, and the extent to which asthma symptoms interfere with daily activities (Roberts, 1995). Traditionally, Asthma severity has been divided into three categories: mild, moderate, and acute/severe. According to Sawyer, Spurrier, and Martin (2001), assessment of severity is generally based on various biomedical indicators, such as bronchial responsiveness and airway inflammation. These biomedical indicators can be influenced by several factors, including treatment compliance, biological responsiveness to medications, or the extent of biological change in children's respiratory systems.

Treatment

Treatment of asthma may take place over decades and involve different types of approaches. Such treatments can include use of medications, self- regulation

and self-management techniques, family systems treatments, and asthma controller therapy (Celano, 2001; Jones, Santanello, & Boccuzzi, 2003). Methods for administering asthma medications can be divided into three broad categories: oral (swallowed pills and liquids), inhalation (via mouth or nose), and injection (into muscle or vein). Forms of medication and treatment vary according to the nature and severity of the asthma episode. Certain treatments, however, are typical. Short-acting inhaled bronchodilators may relieve symptoms of mild asthma attacks. A combination of bronchodilators and anti-inflammatory drugs (e.g., corticosteroids, mast cell stabilizers, and leukotriene modifier drugs) reduce constriction and inflammation of the airways during moderate to severe asthma attacks. A combination of bronchodilators, such as theophylline, and intravenous adrenalin (epinephrine) may also be used for acute asthma attacks (Roberts, 1995; Aschenbrenner, Cleveland, & Venable, 2002; Gaga, Zervas, & Loukides, 2003; Wenzel, 2003; Ducharme, 2003). The use of inhaled steroids (as opposed to oral steroids) is preferred. Anti-allergic medication usually administered by injection desensitizes the asthmatic allergens, and may be used for specific allergy-induced asthma attacks. (National Institute of Health [NIH], 2003).

Studies have shown that individuals may show varying biological responses to medication. In addition, the medication may also result in a number of psychological side effects, such as impeding memory, motor tremors, hyperactivity, and anxiety (Bender, Lerner, & Kollasch, 1988; Bender & Milgrom, 1992; Mazer, Figueroa-Rosario, & Bender, 1990). Therefore, although there are several treatment options for individuals with asthma, the possibility of experiencing side effects is often present.

As noted previously, our understanding of the pathogenesis and treatment of asthma has increased significantly in the recent past, yet morbidity and mortality from the disease have also increased worldwide (Clark, Gong, & Kaciroti, 2001). Indeed, it appears that education involving the effective management of asthma may aid individuals in increasing adherence, recognizing symptoms, and thereby reducing hospitalizations and death. Effective patient self-management appears to be linked to reducing death and disability and increasing functioning among people with asthma (Clark et al., 2001; Guevara, Wolf, & Grum, 2003). Such self-management can include medication and life-style changes, educational programs, changing beliefs about treatment as well as illness perceptions, and the implementation of other behavioral techniques. Several studies indicate that parent and child education regarding behavioral management and self-regulation have positive effects upon self-efficacy and functioning for both the parent and child (e.g., Clark et al., 2001; Evans, Clark, Levison, Levin, & Mellins, 2001; Grus et al., 2001).

To obtain more accurate reports when monitoring compliance, medical and behavioral scientists may make use of objective measures via direct blood serum analysis, and electronic microchip-based recording of medication-taking behavior (Roberts, 1995). Generally, the most successful programs aimed at improving patient compliance are those that are multifaceted in nature. An effective program may include simplifying the dosing schedule, increasing the frequency of contact with the care provider and developing a stronger physician-patient relationship, and providing positive feedback to patients about their level of medication use. In addition, encouraging self-monitoring techniques and providing patients with written

instructions regarding the use of specific medication may aid in making the process of treating asthma clearer and more concrete (Creer, 1993).

Cystic Fibrosis

Description of the Illness

Cystic Fibrosis (CF) is a chronic illness of childhood caused by dysfunction of the exocrine glands (Roberts, 1995). This dysfunction results in production of mucus that is abnormally thick and sticky, thereby causing major problems involving the lungs, pancreas, and bowel. Mucus blocking the pancreatic ducts results in pancreatic insufficiency (the absence of digestive enzymes for the absorption of protein, fat and carbohydrate), as well as inadequate absorption of nutrients. This can result in a voracious appetite, but inadequate weight gain. Mucus accumulates in the lungs, and if not removed, results in over-inflation of the air sacs, causing reduced elasticity. The most serious manifestations of the disease are in the lungs and pancreas, with chronic respiratory disease causing 90-95% of the morbidity and mortality in CF patients (Wood, Boat, & Doershuk, 1995). Lung damage can also occur due to continuous infection of the bronchi leading to gradual weakening of the bronchi walls, deterioration of the lungs, and death. (Hopkin, 1998; Orenstein, 1997). Currently, there is no cure for CF. Treatment revolves around preventing and treating symptoms of the pulmonary disease in an attempt to increase longevity (Stark, Jelalian, & Miller, 1995). As the life expectancy of CF patients increases, other disease complications will emerge, such as abnormal glucose tolerance and possibly diabetes mellitus (Kopelman, 1991).

Incidence and prevalence

Cystic Fibrosis (CF) is the most common genetically based disease of childhood. Estimates of its incidence vary from one in 2500 Caucasians to one in 3300 (NIH, 1997; Willis et al., 2001). Approximately 25,000 people in the United States have been diagnosed with CF, with a rate of newly diagnosed children of approximately 850 per year (NIH, 1997). Most individuals are diagnosed by the age of three; however, nearly 8% of all newly diagnosed cases are 18 or older. It is a progressive and inevitably fatal disease, however, there have been dramatic increases in survival rates in the last few decades (Thompson & Gustafson, 1996). Before 1939, Jackson (1989) reports that most children with CF died before the age of one year. The life expectancy of a child with CF was less than 6 months in the 1950s, but has risen to 30 years in the 1980s (Lewiston, 1985). The median survival rate is now about 40 years (Cystic Fibrosis Foundation [CFF], 2003). According to Willis et al. (2001), prognosis improved markedly with the advances in the medical technologies of early diagnosis and treatment, including physiotherapy, digestive enzymes, antibiotics and nutrition.

Severity

According to Willis et al. (2001), CF is highly variable in its presentation, severity, and course. Some individuals with CF are affected minimally and may not present with the illness until they are in their second or third decade of life. Most, however, are more severely affected and may experience gastrointestinal and/or pulmonary complications from birth. The reasons for the differences in severity are not always known, but may be related to the genetic defect itself, age at diagnosis,

treatment compliance, inattention to nutritional needs, as well as the individual's immune response. The main determinant of both quality of life and longevity appears to be the severity of lung disease, as 90% of individuals with CF die as a result of these pulmonary complications. According to Koller, Gotz, Wojnarowski, and Eichler (1996), the measurement of eosinophil cationic protein (ECP) might be used for clinical monitoring and for assessing disease severity in cystic fibrosis. In addition, Castagna, Roszkowska, Fama, Sinicropi, and Ferreri (2001) found that individuals with CF present with ocular surface abnormalities and lens transparency modifications, and the severity of CF is related to the individual's digestive insufficiency. Therefore, tear tests and cytological procedures might be used as additional tests for assessing the severity of cystic fibrosis. Exercise testing in patients with cystic fibrosis (CF) has become an important tool in assessing disease severity and predicting overall outcome. Other methods of determining the severity of CF include assessing the forced expiratory volume in 1 sec (FEV_1) and measuring arterial blood gases (PO_2 and PCO_2) (Henig & Nguyen, 2002).

Treatment

According to Thompson & Gustafson (1996), the usual treatment regimen for CF involves daily chest physical therapy, diet monitoring, taking multiple medications, and frequent outpatient medical visits. Inpatient hospitalization may also occur when symptoms are severe. Chest physiotherapy (CPT) requires vigorous percussion (by using cupped hands) on the back and chest to dislodge the thick mucus from the lungs. Individuals with cystic fibrosis must eat a well-balanced, high-calorie, high-protein diet. Multivitamins and supplements of the fat-soluble vitamins

(vitamins A, D, E and K) are also important. To enhance digestion, patients need to take supplemental pancreatic enzymes before every meal and snack, and extra enzymes to help digest high-fat foods. Antibiotics are often used to reduce or control infections; drugs known as mucolytics also are utilized to break up the mucus in the lungs. Airway clearance therapies such as recombinant human dornase alpha (rhDNase) are used to reduce airway obstruction (Kling, Gie, & Riphagen, 1997; Ledson, Wahbi, Convery, et al., 1998). Bronchodilators can be used to open the lungs, so more air can enter. Anti-inflammatories such as ibuprofen have been observed to decrease lung inflammation, although they need careful dose administration.

Importantly, there has been development of new treatment technologies (i.e., lung transplants), and the potential for developing a cure for the pulmonary aspect of the disease via gene therapy (Jaffé, Bush, Geddes, & Alton, 1999; Roberts, 1995). Children are usually considered for lung transplantation when their lung disease cannot be significantly improved by either medical therapy or surgery and there is a high probability of death. There are various types of lung transplantations: replacement of one lung (single lung transplantation), replacement of both lungs (double lung transplantation), and replacement of both lungs and the heart (heart-lung transplantation). CF usually requires double lung transplantation. Lung transplantation carries significant risks, such as viral infections and chronic rejection. Such infections can become chronic and cause progressive lung disease (CFF, 2003). According to the United Network for Organ Sharing (2004) the patient survival rates

for all patients that had a lung transplant are 77% at one year, and 58% at three years for patients transplanted between 1996 and 2001.

Researchers are also developing innovative gene delivery systems - or vectors - to determine the best way to deposit healthy genes into the airways of people with CF (CFF, 2003). "Healthy" genes are manufactured in a laboratory using state-of-the-art biotechnology. In 2002, safety and tolerability of the therapy were demonstrated, along with evidence of lung function improvement after gene transfer. CF scientists are hopeful that some of the same technology being developed for gene therapy to treat airway cells will eventually be adapted to treat other organs affected by CF, such as the pancreas (CFF, 2003).

Recently, Taylor, Wallander, Anderson, Brown, & Beasley (2003) conducted a randomized clinical trial of a 3-session written self-disclosure intervention for patients (of at least 15 years of age) with CF. Participants in the intervention were asked to write in the health care setting about an emotionally distressing issue, as well as twice afterwards at home with prompting by phone calls. The patients in the control condition received standard care alone. Findings revealed that the intervention did indeed result in a reduction of the number of days patients spent in the hospital over a 3-month period, although the intervention did not have an impact on physiological or subjective markers of health status. This study demonstrated the effect of the written self-disclosure intervention on health care utilization and justifies further investigation of the modified intervention in other chronic illness populations.

Obviously, there are several types of treatments available for CF. Consequently, a vigorous long-term multidisciplinary treatment program with good follow-up and continuity is extremely important in the treatment of patients with CF (Kempe et al., 1987).

Psychological Factors Associated with Adjustment to Asthma

Much of the current pediatric psychological research to date has sought to determine the extent of the emotional and behavioral adjustment of children with asthma (Eksi, Molzan, Savasir, & Gueler, 1995; Klinnert, McQuaid, McCormick, Adinoff, & Bryant, 2000; McQuaid, Kopel, & Nassau, 2001; Mullins, Chaney, Pace, & Hartman, 1997; Raezer, 1999; Reichenberg, 2002). Indeed, there appears to be an intricate relationship between disease factors, psychosocial aspects, and functional morbidity in pediatric asthma. In a meta-analysis of 78 studies by McQuaid, Kopel, and Nassau (2001), results indicated that children with asthma evidence significantly more behavioral difficulties than do healthy children, with the effect for the internalizing behaviors (e.g., anxiety and depression) being greater than that for externalizing behaviors (e.g., oppositionality, hyperactivity). Specifically, children with asthma may be more likely to exhibit anxious and depressive symptoms than oppositional or hyperactive behaviors, thereby affecting parent-child relationships.

Various studies have shown how factors such as lower socio-economic status (SES), negative life change, family functioning and interaction, and high illness severity can predict less optimal psychological adjustment in children with asthma (Klinnert et al., 2000; MacLean, Perrin, Gortmaker, & Pierre, 1992; Raezer, 1999). Clinical impressions suggest that children with more severe asthma are likely to have

increased functional morbidity (e.g., greater number of missed school days) (McQuaid, Kopel, & Nassau, 2001). A study by Weil et al. (1999) found that the existence of clinically significant behavior problems was associated with poorer functional health status (such as hospitalization and days of wheeze). More recent studies (Klennert et al., 2000; Wamboldt, Fritz, Mansell, McQuaid, & Klein, 1998) have emphasized that contextual factors, such as increased levels of stress and poor management of medication, can often result in adjustment difficulties.

Although there is some debate about the relationship of asthma severity to psychological well-being (Rietveld, Prins, & Colland, 2001), several studies indicate that children and adolescents with asthma are at a greater risk for significant psychological adjustment difficulties when asthma severity is high (e.g., Bennett, 1994; Chaney et al., 1999; McLean et al., 1992; Mullins et al., 1997; Sawyer et al., 2001). These results are supported by the previously mentioned meta-analysis conducted by McQuaid et al. (2001), which demonstrated that internalizing problems (e.g., depression) appear to increase with increasing disease severity.

Naturally, families of children with asthma face a number of challenges related to the disease and its management. As such, research has also focused on adjustment of parents of children with asthma. Townsend et al. (1991) examined the burden experienced by parents of children with asthma. Two major areas of burden for parents were identified: a) interference with daily activities, and b) emotional impact (worry, fear, and concern). As such, it is evident that parents of children with asthma may experience psychological distress from a variety of sources. In addition,

much of this stress is related to parenting a child with asthma, and therefore can be identified as parenting stress.

In a related study, Schulz et al., (1994) examined quality of life factors for 23 parents of 27 children (mean age 7.78 yrs) with asthma. The researchers reviewed the 84 most recently received letters sent to MA (Mothers of Asthmatics, Inc./The National Allergy and Asthma Network) to identify issues and concerns reported by parents in their own words. The issues raised in these letters served as a general guide for three focus group interviews conducted in a convenience sample of parents of children with asthma in South Carolina (Schulz, et al., 1994). The focus groups were tape-recorded and transcribed, and the transcriptions yielded more than 400 specific statements by parents relating to their quality of life. The list of statements was condensed to 326 unique statements. These statements were reviewed by a 9-member research team who, in turn, eliminated 110 statements, leaving 216 statements. This process of reducing the number of items yielded a total of 19 separate categories. In brief, the researchers found that caring for a child with asthma had significant emotional impact on these parents. Several factors were also identified that negatively influenced the psychological well-being of the parent, including parental over-involvement with the child, the organization of the family around the child's condition, sibling resentment, manipulative behavior of the child, and family hopelessness, helplessness, and frustration. The parents reported that much of their helplessness and hopelessness occurred through unsatisfactory encounters with schools, physicians, and insurance companies. Also, they reported feeling frustration

in trying to balance their own needs, goals, and desires with the requirements of caring for a child with asthma.

A more recent study investigated the relationship between parental self-efficacy and asthma-related morbidity (Grus et al., 2001). Participants in the study included 139 parents of children (ages 5-8) who were diagnosed with asthma and were primarily from lower-income and minority backgrounds. The parents completed a 22-item measure of self-efficacy, a 17-item measure designed to assess recent asthma symptoms, and a 14-item questionnaire that provided a measure of the child's capacity to perform age-appropriate activities. Results indicated a negative relationship between parental perceptions of self-efficacy and asthma-related morbidity. Interestingly, the relationships were strongest for the parents who were high on the learned helplessness factor. More specifically, parents who reported that they were less able to manage their child's asthma and their lives effectively were also more likely to experience asthma-related morbidity. These results suggest targeting parental self-efficacy may be a useful component of an intervention program with this population.

Obviously, a complex relationship exists between disease factors and psychological factors in pediatric asthma. The studies discussed above have demonstrated that in general, children with asthma experience more behavioral difficulties as well as more externalizing symptoms than healthy children. Asthma severity has been shown to play a role in the psychological adjustment of children, as well as negatively affecting parental perceptions of self-efficacy and possibly increasing parental over-involvement. The extant data suggests that these parents and

children are at heightened risk for the development of psychological problems and difficulties which can ultimately affect their psychological adjustment and relationship with each other.

Psychological Factors Associated with Adjustment to Cystic Fibrosis

As mentioned previously, Cystic Fibrosis (CF) is a progressive disease with no known cure, although advances in diagnosis and treatment have resulted in patients living substantially longer. Nevertheless, a child diagnosed with CF must adjust to multiple demands and potential stresses (Roberts, 1995). The extant literature would indeed suggest that these children are at risk for adjustment problems. As but one example, Thompson, Gustafson, Hamlett, and Spock (1992) utilized structured interviews and self-report inventories with 45 children diagnosed with cystic fibrosis (aged 7-12 yrs). They found that 62% of the children met criteria for a DSM-III diagnosis, with mixed internal and external behavior problem patterns and diagnoses of anxiety and oppositional disorder being more frequent. There are some data also suggesting an increased incidence of anxiety-related concerns, particularly somatic complaints, in children with CF compared to peers who are not chronically ill (Roberts, 1995). More recent studies have also found a risk for anxiety in children and adolescents with CF, as well as a risk for behavioral disturbances (Thompson, Gustafson, Gil, Godfrey, & Bennett-Murphy, 1998; Thompson et al., 1992).

Recent studies have also sought to determine the relationship of various risk factors to the psychological adjustment of children with CF (Pumariega, Pearson, & Seilheimer, 1993; Raezer, 1999; Thompson et al., 1998; Thompson, Gil,

Gustafson, & George, 1994; Thompson, Gustafson, & Gil, 1995; Thompson, Gustafson, Gil, Kinney, & Spock, 1999). Among others, levels of maternal distress, levels of daily stress, impact of the illness on the family, familial adaptation, illness severity, and family conflict constituted risk factors in the psychological adjustment of children with CF.

In one of the few longitudinal studies, Thompson, Gustafson, George, & Spock (1994) addressed the stability over a 12-month period of mother-reported and child-reported adjustment, child adaptational processes, illness severity, and maternal adjustment, and the relationship of child adaptational processes and maternal adjustment to child adjustment in 41 children with cystic fibrosis aged 7-14 years. Mother and child-reported adjustment problems remained relatively constant over the 12-month period. However, there was less stability in the classification of adjustment in specific behavior problem patterns and diagnoses and in child-reported adjustment than in mother-reported adjustment. Children's perceptions of self-worth significantly influenced child-reported symptoms and mother-reported adjustment at follow-up. Also, maternal distress accounted for a significant increase in child-reported symptoms. This last finding further supports the idea that the adjustment of children with a chronic illness can be influenced by the parents' adjustment.

In 1999, Thompson, Gustafson, Gil, Kinney, and Spock tracked changes over a 2-year period in the psychological adjustment of 59 children with CF and 50 children with sickle cell disease aged 7-17 years old and their mothers. Their results indicated that stability of individual differences in adjustment was low, and varied as a function of informant and illness type. Further, their results indicated that

adjustment in children with sickle cell disease appeared to be higher than that of children with cystic fibrosis.

Thompson et al. (1998), identified illness-specific patterns of adjustment and cognitive adaptational process in children (aged 7-12 yrs) with cystic fibrosis (n = 40) or sickle cell disease (n = 40). Their protocol included self-report questionnaires and structured interviews that were completed by both children and their mothers. The researchers found a higher rate of oppositional behavior in children with CF than children with sickle cell disease. Also, there were different patterns of relationships among the cognitive processes and adjustment within the illness subgroup. Children with CF had higher levels of self-reported oppositional behavior and behaviors associated with attention deficit disorder, than did children with SCD. Further, the frequency of externalizing disorders, particularly oppositional disorder and conduct disorder, were higher in children with CF than children with SCD (Thompson et al., 1998). These findings provide support for the hypotheses of illness-specific patterns of adjustment and cognitive adaptational processes in children with different chronic illnesses.

A more recent study by Raezer (1999) was conducted on ninety-two mother/child dyads (forty children with cystic fibrosis and fifty-two children with asthma). Subjects were recruited for the study during their regularly scheduled clinic visit to a pediatric pulmonary outpatient clinic. Measures used included the Child Behavioral Checklist (CBCL) to assess child psychosocial adjustment, the Child Assessment Schedule (CAS), a semi-structured interview for children that generates psychiatric symptom information, and the Revised-Children's Manifest Anxiety Scale

(RCMAS), a brief self-report inventory that measures the level and nature of anxiety in 6- to 19-year-olds. Results indicated that children with CF, particularly those with severe CF, demonstrated more adjustment problems, such as oppositional behavior, than children with asthma.

To sum, the extant research has shown that children with cystic fibrosis experience various types of adjustment difficulties as well as anxiety-related problems. The literature reviewed above has compared children with CF to healthy populations, as well as to children with other types of chronic illnesses. Yet it is not only the child who experiences problems with psychological adjustment. Parents and families of children with CF have been shown to experience higher levels of stress, parenting stress, anxiety, and depression, than the general population.

Due to treatment advances and increased longevity, families live with the illness for longer periods (Foster et al., 2001). According to Foster et al. (2001), demanding, time-consuming treatment, coupled with the progressive nature of CF, promote high levels of parental involvement for younger children as well as older teenagers, often due to attempted or actual non-adherence. These demands potentially can have serious consequences for the psychological well-being of parents of children with CF. As the illness occurs within the context of ongoing developmental processes, the family constantly has to adapt to new demands and challenges placed on it by the disease and daily life in general (Foster et al., 2001; Mullins, Olson, Reyes, & Bernardy, 1991).

Researchers have long suggested that parents of children with CF are subject to high levels of stress, and may be at increased risk for psychological

disturbance (Lewiston, 1985). In early studies, relatively high frequencies of psychiatric symptoms, particularly depression and anxiety, were reported among mothers of CF patients (Breslau, Staruch, & Mortimer, 1982; Bywater, 1981; Lawler, Nakielny, & Wright, 1966; Walker, Ford, & Donald, 1987). These older studies contained several methodological problems, such as small numbers of participants, higher proportions of individuals with advanced disease, cross-sectional designs, and uni-dimensional approaches that focused on the individual child and parent variables in relation to disease states (Anderson & Auslander, 1981).

Current perspectives include an “interactional” or “transactional” approach, where coping is viewed as a complex function of person, disease, and environmental factors (Belsky, 1981; Johnson, 1988). Using standardized measures of adjustment, Mullins et al (1991) revealed that as a group, mothers of CF children were characterized by problematic functioning, with evidence for higher yet sub-clinical levels of general distress, depression, anxiety, and hostility. These results suggest, however, that while mothers of children with CF evince higher levels of distress compared to available norms, they by and large appear to cope well.

Thompson, Gil, Gustafson, and George (1994) conducted two longitudinal studies of 117 mothers of children and adolescents with cystic fibrosis and sickle cell disease to identify the frequency and types of adjustment problems. Stable poor maternal adjustment was associated with higher levels of appraisal of daily stress and palliative coping and low levels of family supportiveness. In addition, they found that illness severity, child psychological adjustment, and family conflict added significant increments to maternal adjustment at follow-up in the CF group.

In sum, the current literature indicates that not only are children at risk for adjustment problems, but parents can be negatively affected as well. Certainly, the demanding nature of CF subjects parents to high levels of stress, and thereby increases the risk for psychological difficulties.

Discrete Parent Variables and Adjustment to Chronic Illness

It can be argued parents of children with asthma and CF are at risk to experience higher levels of both general and illness-related stress. The emotional and physical challenges of providing care for a child with a chronic disease usually interrupts normal family functioning, and can potentially lead to impaired relationships between parents and their children. Complex treatment, poorer child health status, and higher levels of stressful family life events are factors that may contribute to higher personal stress levels, potentially resulting in increases in parenting distress and ultimately changes in parenting approaches.

Indeed, parents of children with asthma and parents of children with CF must deal with the emotional impact of the chronic illness, and will experience worry and concern for the safety and well being of their child. An overprotective parenting approach is likely to develop in families with chronically ill children, as most chronic illnesses and physical disabilities require intensive medical management and, as a consequence, place considerable physical, psychological, and social demands on the individuals and families involved (Holmbeck et al., 2002). Therefore, children with asthma and CF are potentially at risk for overprotection, as the parents are at risk to engage in overprotective behaviors. To date, no research has been conducted on families of children with asthma or CF to document levels of overprotection and

parenting stress. In the section to follow, the constructs of parental overprotection and parenting stress will be reviewed.

Parental Overprotection

Parental overprotection is best described by the parent who is highly supervising, has difficulties with separation from the child, discourages independent behavior, and is highly controlling (Thomasgard & Metz, 1999). The concept of overprotection was first described by Levy (1931, 1966), who outlined four characteristic dimensions of the overprotective parent: 1) excessive physical or social contact, 2) prolonged infantilization, 3) active discouragement of independent behavior and social maturity, and 4) either a dominating excess or an overindulgent absence of parental control (Thomasgard & Metz, 1997).

Parental overprotection (OP) has been more recently defined as a level of maternal or paternal protection that is excessive, taking into account the developmental level and abilities of the child (Holmbeck et al., 2002; Thomasgard, Metz, Edelbrock, & Shonkoff, 1995). It can be regarded as a specific pattern of behaviors whose function is to ensure the safety of the child. Parental overprotective behaviors have also been characterized as being more restrictive and controlling (Parker, 1981; 1983; 1993). Parental overprotection may be more likely to develop in families with chronically ill children. Indeed, in such an environment, increased levels of parental protection may be adaptive as parents attempt to maintain the health of their child and regulate their own exposure to stress (Holmbeck et al., 2002). In other words, what begins as well-intentioned parental helping is transformed through excessive protection. This occurs as a result of the parent trying to make sure the

child follows the treatment regimen while, at the same time, trying to balance the development of the child's self-governance skills. As the helping process evolves, tension may develop between parent and child as the parent's investment in facilitating positive health outcomes conflicts with the child's developing autonomy (Holmbeck et al., 2002). According to Thomasgard (1998), overprotection suggests behaviors that go beyond what most parents would do in similar circumstances; such behaviors can have deleterious effects on both the child/adolescent and the parent. These deleterious effects may include increased stress, psychological dysfunctions, an indulgent form of parent-child relationship, as well as an increasingly conflicted parent-child relationship.

Empirical research on the parental overprotection construct has just begun to emerge in the last decade. Retrospective studies (Parker, 1983) supported a link between parental overprotective behavior and an increased risk for adult dysthymia and anxiety disorders (Thomasgard & Metz, 1997). In 1979, Parker and Lipscombe sought to determine if parental overprotection was an antecedent or a consequence of asthma in a child. Fifty asthmatic, 50 nonasthmatic siblings, and 50 healthy control participants rated their parents on the Parental Bonding Instrument, a measure of fundamental parental styles as perceived by the child. Their results suggested that parental overprotection was a consequence of asthma in a child, although this was more clearly demonstrated for the fathers than for the mothers. The authors argued that parental overprotection associated with asthma was likely to reflect an adaptational response by parents to a child with a chronic, unpredictable illness arousing high levels of anxiety in parents.

In 1995, Thomasgard, Metz, Edelbrock, and Shonkoff developed a measure of parental protective behaviors toward children (aged 2-10 years), the Parent Protection Scale (PPS). Parents (n = 892) of children aged 2-5 years and parents (n = 280) of children aged 5-20 years were recruited from pediatric physicians' offices. Items were selected to represent key dimensions of protective behaviors. Factor analyses suggested four subscales: supervision, separation problems, dependency, and control. The authors suggested that higher total PPS scores among younger parents may reflect more uncertainty and anxiety about their own parenting competence, resulting in closer supervision and control of their children (Thomasgard, et al., 1995). The PPS demonstrated acceptable internal consistency, test-retest reliability, and clinical validity.

Further research by Thomasgard et al. (1995) examined perceived vulnerability of children and overprotection in parents of 2-5 year old children. Parents (n = 892) completed a 3-part protocol, consisting of clinical background data, the Child Vulnerability Scale, and the Parent Protection Scale. Significant correlates of high parental overprotection included younger age of the child, younger age of the parent, single parenthood, and lower SES. In addition, results provided significant support for the need to distinguish between parental perceptions of child vulnerability and parental overprotective behaviors. Their data indicated that parental perception of increased child vulnerability and parental overprotective behaviors are not synonymous and represent separate constructs. The authors proposed that this study provides a preliminary step in unraveling the mechanisms (e.g., shared health experiences, parents' childrearing histories) that contribute to the interplay among

parental anxieties, the parent-child relationship, and child behaviors (Thomasgard et al., 1995).

Thomasgard & Metz (1996) also conducted a longitudinal study examining the stability and child behavioral correlates of parental perceptions of increased child vulnerability and parental overprotection over a 2-year period. Results indicated that the 2-year stability of high parental overprotection was 37%. For high parental perception of child vulnerability, stability was 31%. High perceived vulnerability at enrollment was significantly associated with parent reports of problematic behaviors at follow-up. However, a history of overprotection in the parent's childhood was not associated with current parental report of overprotective behaviors toward the child.

In 1997, Thomasgard & Metz further examined the correlates of parental overprotection and parental perceptions of increased child vulnerability in 280 parents of children aged 5 and 10 years old. Parents were recruited from two pediatric office sites. An assessment protocol that included demographic and clinical background data, the Parent Protection Scale (PPS), and the Child Vulnerability Scale (CVS) was administered to the parents. Two significant correlates of parental overprotection were revealed, namely younger age of the child and less parental education. Approximately a third (35%) of parents who considered their child vulnerable were also classified as overprotective. The researchers suggested that continued research from both the pediatric and psychiatric perspectives is needed to clarify better the natural history and optimal clinical management of such clinically prevalent parent-child relationship disturbances.

Notably, Holmbeck et al. (2002) conducted a study to test a mediational model of associations between parental overprotectiveness, behavioral autonomy, and psychosocial adjustment. The sample included 68 families with 8- and 9-year-old preadolescents with spina bifida and a demographically matched sample of 68 families with able-bodied children. On the basis of both questionnaire and observational measures of overprotection, mothers and fathers of children with spina bifida were significantly more overprotective than their counterparts in the able-bodied sample. Parental overprotection was associated with lower levels of preadolescent decision-making autonomy. It was also associated with parents being less willing to grant autonomy to their offspring in the future. Further, a mediational model was supported such that parental overprotection was associated with less behavioral autonomy, which was, in turn, associated with more externalizing problems in children with spina bifida. Parental overprotection therefore has implications not only for the psychological well being of the parent, but also for the adjustment of the child.

In 2003, Power et al. examined the degree to which mothers of children with juvenile rheumatoid arthritis (JRA) show an overprotective or highly controlling interaction style. Forty-two children with JRA (aged 6 to 13-years-old), who were seen in the rheumatology outpatient clinic over a 2-year period, and their mothers were recruited for the study. A comparison group of 42 healthy children and their mothers were also included. An assessment protocol that included demographic data, medical status and physical limitations data, and a mother-child interaction task was administered to the child-mother dyads. There were no differences between mothers

of children with mild arthritis and the healthy comparison groups). However, it was found that there were several differences between mothers of children with severe arthritis and healthy comparison groups. Mothers of children with more severe arthritis were more directive of their children's behavior during the task, demonstrating higher rates of structure and rule setting, general clues, and prompting the child to answer. These findings further support the literature suggesting that parents of children with chronic illness are at risk for more overprotective, overcontrolling, or intrusive interaction styles that may interfere with the child's developing autonomy (Thomas et al., 2003).

In a 2003 study, Anthony, Gil, and Schanberg further demonstrate how parental perceptions and interaction style may negatively influence the social and psychological adjustment of the child. Anthony, Gil, and Schanberg (2003) examined the extent to which parental perceptions of child vulnerability predict school and social adjustment in 69 children with a well-defined pulmonary or rheumatic disease. Parents completed a self-report measure of parental perceptions of child vulnerability, and children completed measures of social adjustment. The researchers also obtained the parents' permission to obtain school attendance records. It was found that increased parental perceptions of child vulnerability were related to increased social anxiety in children, even after controlling for child age and disease severity. Further, lower levels of parental education related to both increased perceptions of child vulnerability and increased school absences. The results suggest that parents of children with chronic illness generally have increased perceptions of child vulnerability (Anthony et al., 2003). In addition, the results demonstrate how parental

perceptions and interaction style may influence the social and psychological adjustment of the child.

Recent research conducted by Mullins et al. (2004) examined parental overprotection and perceived child vulnerability in relation to self-reported depressive symptoms in 8- to 12-year-old children diagnosed with DM1. In addition, the moderating influence of parenting stress was examined. Parental overprotection, perceived child vulnerability, and parenting stress measures were completed by the mothers (n = 43). Child participants completed a measure of depressive symptomatology. Both child vulnerability and parenting stress were associated with higher levels of depressive symptoms, although no relationship was found between overprotection and child depressive symptoms. Regression analyses revealed that parenting stress moderated the relationship between perceived child vulnerability and depressive symptomatology. Therefore, it appears that parenting stress magnifies the relationship between perceived child vulnerability and child-reported depressive symptoms. The findings provide additional empirical support for the transactional relationship between discrete parenting variables and child distress. The results also support the idea that although overprotection and child vulnerability overlap, they are distinct constructs. The authors suggest that interventions that target specific parenting approaches and general parenting stress may be effective in reducing the levels of distress experienced by children.

Notably, there has been significant research conducted concerning the construct of overprotection. Studies indicate that overprotection is more likely to develop in families with chronically ill children, as a type of adaptational response.

However, overprotection can have negative effects on both the parent and child, such as increased stress and psychological problems (e.g., anxiety disorders). Further, children are more at risk for developing less behavioral autonomy and more externalizing problems. Recent research has also begun identifying correlates of overprotection (e.g., younger age of the child and less parental education), as well as the effects of other psychological constructs (e.g., parenting stress) upon overprotection.

Parenting Stress

In the healthy population, parenting stress has been associated with low parenting satisfaction, less social support, higher psychological and somatic symptomatology in parents (Koeske & Koeske, 1990), abusive behavior (Kelley, 1998; Rodriguez & Green, 1997; Whipple & Webster-Stratton, 1991), and insecure child attachment (Hadadian & Merbler, 1996; Jarvis & Creasey, 1991). Past research has also consistently demonstrated that mothers of children with a chronic illness are at risk for experiencing such increased levels of stress (e.g., Thompson, 1986; Wallander, 1993). Increased levels of stress have been linked to the adjustment of parents of chronically ill children (e.g., Thompson, Gil, Burbach, Keith, & Kinney, 1993; Mullins et al., 1991). Such stressors can be directly or indirectly related to the child's illness. Thus, stressors that are independent from the child's illness, i.e., daily stressors, may be present (Manuel, 2001). As an example, Manuel (2001) found that daily stress was the strongest predictor of parental distress, followed by illness-related stressors, in a sample of ninety-two mothers of children diagnosed with Juvenile Rheumatic Arthritis.

It is important to distinguish between general psychological stress and parenting stress, as the latter is the focus of this paper. Parenting stress is defined as stress that is associated with the parenting of a child. It is a specific kind of stress, perceived by the parent and emanating from the demands of being a parent (Abidin, 1990). Parenting stress may be directly related to stress subsequently experienced by children facing health threats (Johnson & Tercyak, 1995; Melamed & Ridley-Johnson, 1988; Streisand, Braniecki, Tercyak, & Kazak, 2001). It is notable that the psychological distress arising from parenting stress can potentially contribute to the development of dysfunctional parent-child relationships and constitutes a risk factor for both child and adult psychopathology (Abidin & Brunner, 1995; Deater-Deckard, 1998; Reitman, 2002). Although a complete review of the literature pertaining to parenting stress is beyond the scope of the present paper, those studies that relate specifically to children with chronic illness will be reviewed below.

To date, relatively few studies have focused specifically on parenting stress in the context of the chronically ill child. In one of the first studies with chronically ill children, parenting stress was examined in parents of children with either cystic fibrosis (CF), chronic heart disease (CHD), or no chronic health problems (Goldberg, Morris, Simmons & Fowler, 1990). The responses on the Parenting Stress Index of 30 parents of children with cystic fibrosis (CF), 52 parents of children with congenital heart disease (CHD), and 60 parents of healthy babies were compared. Three domains of stress were distinguished, including parent, child, and life events domains. Results indicated that parents in the CHD group reported the highest levels of life events stress, and parents in the CF group reported more stress

arising from the child's demandingness. Notably, the parents of infants with CF and CHD reported more problems with depression and a lowered sense of competence compared with parents of healthy children. Such data suggests that parents of children with chronic illnesses are indeed at risk for experiencing higher levels of emotional and physical stress than that of the general population.

Frank, Olmsted, Wagner, and Laud (1991) subsequently assessed the relationship between minor illnesses that children evidenced in the first 3 years of life, and parenting stress in the 4th year of life. The moderating influence of parenting alliance was also examined. Results indicated that parenting alliance was more strongly related to parenting stress for fathers than for mothers. However, child morbidity and parenting alliance interacted in predicting child-related paternal stresses. These outcomes also suggest that pediatric parenting stress and family functioning are interrelated constructs and, as such, need to be investigated in more detail in samples with a chronic illness.

Using the Parenting Stress Index and the Mother-Child Relationship Evaluation measure, perceptions of parenting stress and the mother-child relationship were evaluated by Carson and Schauer (1992) in 41 mothers of asthmatic children. Results indicated that perceived parenting stress was greater and the quality of the mother-child relationship was more problematic for mothers of asthmatic children than for mothers of healthy children. Mothers rated their asthmatic children as more stressful in terms of various child characteristics, including adaptability, acceptability, demandingness, mood, and extent to which the child was reinforcing of the parent. Further, mothers of asthmatic children tended to show higher levels of rejecting,

overprotectiveness, and overindulgence than mothers in normative groups. This study further supports the research indicating that parents of chronically ill children are at a higher risk for experiencing parenting stress and, possibly as a result, psychological distress and parental overprotection.

Kazak and Barakat (1997) also used the PSI (PSI; Abidin, 1995) to evaluate relationships between parenting stress and parent-related child quality of life during treatment for childhood leukemia. A strong association was seen between parenting stress during treatment and later parental adjustment for both mothers and fathers. More specifically, it was found that higher levels of parenting stress were associated with a lower quality of later parental adjustment. As a result, parenting stress was seen to influence the quality of psychological adjustment in parents of chronically ill children.

Smith, Oliver, and Innocenti (2001) further examined parenting stress in 880 families of children who were moderately to severely developmentally delayed. Using the Battelle Developmental Inventory (BDI), the Parenting Stress Index – Short Form (PSI/SF), the Beck Depression Inventory (BDI), and the Family Support Scale (FSS), they determined the relative weight of both family and child functioning variables in predicting parenting stress. Their results indicated that factors such as income, time available for interaction with the child, and social support predicted parenting stress better than the severity of the child's disability. Indeed, this study suggests that the severity of a disability may have no significant effect on a parent's level of parenting stress. The role of social support and other systemic variables is again shown to play an important role in the development of parenting stress.

Recently, Streisand et al. (2001) developed a measure of parenting stress related to caring for a child with an illness and evaluated its psychometric properties with a group of parents of children with cancer. The 42-item self-report Pediatric Inventory for Parents (PIP) was administered to 126 parents. Their results indicated that internal consistency reliability was high (Cronbach alpha range .80 - .96). In addition, PIP scores were significantly correlated with a measure of state anxiety, indicating that construct validity was also high. The authors suggest that the PIP may be used to provide information about parent well-being that extends beyond that obtained from more general measures. Streisand, Kazak, & Tercyak (2003) subsequently investigated parenting stress and family functioning outcomes by administering the PIP and the McMaster Family Assessment Device (FAD) to 116 parents of children treated for cancer. Results indicated that parenting stress was significantly correlated with family functioning, with higher levels of pediatric parenting stress being associated with poorer family functioning outcomes.

More recent research conducted by Macias et al. (2003) examined whether ages of child and parent were risk factors for general parenting stress and disability-specific stress in families of children with spina bifida. The PSI/SF, Parents of Children with Disabilities Inventory, and measures of family support and resources were administered to parents of 64 children with spina bifida. The scores obtained from families with children under 6 years versus 6 - 12 year old children were compared. Also, scores of mothers above or below the age of 35 years were obtained and compared. No associations between the ages of the child and parent, and medical severity, socioeconomic status, family resources, or family support were detected.

However, as the children become older, and disability-related differences become more apparent, the same level of functioning and severity of disability was associated with additional parenting stress. These results suggest that older mothers and those with school-age children may need more resources than current social support systems typically provide. Consistent with the systemic nature of these multivariate relationships, it is evident that there are several pathways towards the development of parenting stress, which may lead to negative physical and psychological effects on the child.

Parenting stress may then exert influences on the child and family adjustment outcomes. Mullins et al. (2004) found parenting stress to be associated with higher levels of depressive symptomatology in children, and, to magnify the relationship between perceived child vulnerability and child-reported depressive symptoms. Additionally, a recent empirical study by Streisand, Kazak, & Tercyak (2003) evaluated the association between pediatric parenting stress and family functioning outcomes in 116 parents of children treated for cancer. Parenting stress was defined as the stress related to caring for a child with a medical illness. The results indicated that pediatric parenting stress was significantly correlated with family functioning. Furthermore, after controlling for child treatment status, the scores indicated that increased parenting stress is associated with poorer family functioning outcomes.

Taken together, the studies discussed above suggest that parenting stress is a salient psychosocial factor that negatively influences parents of chronically ill children, as well as the children themselves. Parenting stress has been associated with

somatic symptomatology in parents, abusive behavior, and can potentially contribute to a dysfunctional parent-child relationship and adaptive functioning in children. However, the extant research literature has not investigated the relationship of this variable to parental adjustment in chronically ill populations, nor have many comparisons of chronic illnesses been examined. In addition, studies have not explored the relationship of both parenting stress and parental overprotection to parental adjustment. In the current study, the relative influences of both parenting stress and parental overprotection on parental adjustment were investigated both within and across two different pulmonary diseases.

CHAPTER III

PURPOSE OF THE PRESENT STUDY

The overall purpose of the present study was to evaluate the relationship of parental overprotection and parenting stress to psychological distress across two pulmonary diseases. The study evaluated group differences between the two disease states on dimensions of parental overprotection and parenting stress. This research addressed the following questions:

1. Do mean levels of parental overprotection, parenting stress, and psychological distress differ in mothers of children with CF compared to mothers of children with asthma?
2. Do parental overprotection and parenting stress have independent effects on psychological distress?
3. Will differential correlational relationships exist between parental overprotection, parenting stress, and psychological distress within the two illness group?

The following hypotheses were proposed:

1. Higher mean levels of parental overprotection, parenting stress, and psychological distress will be found in mothers of children with CF compared to mothers of children with asthma.
2. Parental overprotection will be significantly related to psychological distress within each illness group.

3. Parenting stress will be significantly related to psychological distress within each illness group.
4. Differential correlational relationships will exist between parental overprotection, parenting stress, and psychological distress within the two illness groups.

For exploratory reasons, the following research question will be posed:

1. What are the independent contributions of parental overprotection, parenting stress, illness parameters, and demographic parameters to psychological distress within the combined group?

CHAPTER IV

METHOD

Participants

Participants included mothers of children with asthma and CF (between the ages of 2 and 18). They were recruited from four separate pediatric practices in the Southwest. Inclusion criteria for participation were that individuals (a) have a child who has not been diagnosed with another chronic illness beside asthma or cystic fibrosis, and (b) their child does not evidence a developmental disability.

Ninety-two mothers of children with asthma and forty-nine mothers of children with CF were recruited into the study. See Table 1 in Appendix F for descriptive information about the asthma and CF groups. Mothers in the asthma group (AS) ranged in age from 24- to 53-years ($M = 38.90$, $SD = 5.87$), and children in the AS group ranged in age from .9- to 18-years ($M = 10.02$, $SD = 3.64$). Mothers in the CF group ranged in age from 24- to 51-years ($M = 37.46$, $SD = 6.68$), and children in the CF group ranged in age from .7- to 18-years ($M = 9.98$, $SD = 4.78$).

Children in the AS group were predominantly Caucasian (87%), with the remainder of the participants endorsing African-American (7.6%), Native American (3.3%), or Other (2.2%) ethnicity. Children in the CF group were also predominantly Caucasian (87.8%), with the remainder of the participants endorsing Native American (10.2%), or Other (2%) ethnicity.

In the AS group, the duration of the illness ranged from .08- to 16-years ($M = 7.73$, $SD = 3.85$). In the CF group, the duration of the illness ranged from .67- to 17-years ($M = 8.76$, $SD = 5.13$).

Mothers in the AS group ranged in education from 11- to 20-years ($M = 14.96$, $SD = 2.43$). Mothers in the CF group ranged in education from 9- to 20-years ($M = 14.26$, $SD = 2.10$).

Mothers in the AS group were predominantly married (79.3%), with the remainder of the participants endorsing single (10.9%), remarried (5.4%), never married (1.1%), or other (1.1%) marital status. Mothers in the CF group were also predominantly married (71.4%), with the remainder of the participants endorsing single (10.2%), remarried (6.1%), never married (2%), or other (10.2%) marital status.

In both groups, family income ranged from \$0 - \$4,999.00 to \$60,000.00 – greater. Categories included 1 (\$0 - \$4,999.00), 2 (\$5,000 - \$9,999.00), 3 (\$10,000.00 - \$14,999.00), 4 (\$15,000.00 - \$19,999.00), 5 (\$20,000.00 - \$29,999.00), 6 (\$20,000.00 - \$39,999.00), 7 (\$40,000.00 - \$49,999.00), 8 (\$50,000.00 - \$59,000.00), and 9 (\$60,000.00 – greater). Family income for the AS group was as follows: 37% made \$60,000.00 – greater, 13% made \$20,000.00 - \$29,999.00, 13% made \$20,000.00 - \$39,999.00, 10.9% made \$50,000.00 - \$59,000.00, 9.8% made \$40,000.00 - \$49,999.00, 4.3% made \$0 - \$4,999.00, 3.3% made \$5,000 - \$9,999.00, 3.3% made \$10,000.00 - \$14,999.00, and 2.2% made \$15,000.00 - \$19,999.00. Family income for the CF group was as follows: 30.6% made \$60,000.00 – greater, 12.2% made \$20,000.00 - \$39,999.00, 12.2% made \$50,000.00 - \$59,000.00, 10.2%

made \$5,000 - \$9,999.00, 10.2% made \$10,000.00 - \$14,999.00, 8.2% made \$40,000.00 - \$49,999.00, 6.1% made \$20,000.00 - \$29,999.00, 4.1% made \$0 - \$4,999.00, and 2% made \$15,000.00 - \$19,999.00.

Procedure

All potential participants were sent a letter informing them of the nature of the study. The letter included a postage-paid postcard that the participants could return if they were interested in participating. Names and addresses of potential participants were obtained from the pediatricians and solicitations were sent out to those families. After receiving the postcard, families that wished to participate in the research were sent a testing packet that contained a detailed cover letter, a consent form, and a testing battery that included several measures. The estimated completion time for these packets was approximately 45 minutes to 1 hour. After completing all the measures in the packet, participants could return the materials to the researcher by using the enclosed self-addressed stamped envelope.

Measures

Background Information Questionnaire. Demographic data was obtained by asking parents to provide basic information about themselves and their child. Information that was collected included the child's gender, age, and grade, parents' age, marital status, occupational status, as well as current members of the household.

Health Care Utilization Questionnaire (HCUQ). Parents were asked to complete the HCUQ, which is designed to assess information related to the use of health care resources for the child with asthma or cystic fibrosis. Specific questions tap into the number of inpatient and outpatient visits, emergency room visits, and

hospitalizations the child has experienced over the past year. This measure also contains items pertaining to the amount of money spent in treating their child's illness, and amount of time spent working with health care agencies in managing the financial aspects of their child's illness. Parents were also asked to complete several Likert-style ratings that assessed their level of stress for financial strain produced by their child's illness, as well as items regarding their relationship with their child's doctor or treatment team.

The Parent Protection Scale (PPS). The PPS is a 25-item scale designed to assess specific items of parenting behavior related to child autonomy, individuation, and separation. Representative items from the PPS include: "I comfort my child immediately after he/she cries," "I let my child make his/her own decisions," and "I feed my child even if he/she can do it alone." Higher total scores represent greater overall levels of parental protection behaviors. Normative studies on the PPS have demonstrated moderate to high internal reliability ($\alpha = .73$) and high test-retest reliability for the total score ($r = .86$, $p = .001$; Thomasgard et al., 1995). Criterion validity using criterion-referenced clinical history as the basis for comparison has also been demonstrated to be acceptable: sensitivity = 71%, specificity = 94%, and positive predictive value = 92% (Thomasgard, et al., 1995). The score used in the analyses is the total score that is derived from the sum of all 25 items, with a possible range from 0 to 75. Higher scores represent greater levels of parental overprotection.

The Parenting Stress Index - Short Form (PSI-SF). The Parenting Stress Index (PSI; Abidin, 1995) was created to sample a diverse range of potential

influences on parenting practices. To address the need for a psychometrically sound but brief screening measure of parenting stress, Abidin developed the 36-item PSI-Short Form (PSI-SF). The PSI-SF was derived from a series of exploratory factor analyses of the full PSI, and yields three subscales, including Parental Distress, Parent Child Dysfunctional Interactions, and Difficult Child, as well as a summary score. The summary score was used in all analyses. Representative items from the PSI-SF include: “I feel trapped by my responsibilities as a parent,” “My child rarely does things for me that make me feel good,” and “My child turned out to be more of a problem than I had expected.” The PSI-SF is highly correlated with the full-length PSI instrument ($r = .94$) and two-week test-retest reliability of the full-length PSI with the PSI-SF is .95 (Abidin, 1990). Internal consistencies for the PSI-SF have been found to range from very good to excellent (Roggman, Moe, Hart, & Forthun, 1994; Reitman, Currier, Stickle, 2002). In addition, Abidin (1995) reported that Total Stress scores on the PSI correlated .94 with the PSI-SF total, the PSI Parent Domain correlated .92 with Parental Distress on the PSI-SF, and the PSI Child Domain correlated .87 with the Difficult Child subscale on the PSI-SF.

The Brief Symptom Inventory (BSI). The BSI is a 53-item self-report measure which asks parents to rate their level of psychological distress during the past seven days (Derogatis, 1993). Parents are presented with brief statements tapping into domains associated with distress and are asked to complete Likert-style ratings ranging from “not at all distressed” (0) to “extremely distressed” (4). Representative items from the BSI include: “Feeling easily annoyed or irritated,” “Difficulty making decisions,” and “Feeling tense or keyed up.” The BSI is scored in terms of nine

clinical dimensions of psychological distress, with t-scores ranging from 30 to 80. Previous research has demonstrated that the BSI has high internal consistency ranging from .71 to .85, as well as high test-retest reliability ranging from .68-.91 (Derogatis, 1993). It has a test-retest reliability coefficient of .90, thereby providing evidence of being a consistent measure across time (Derogatis, 1993). The BSI instrument also provides a Global Severity Index (GSI), which gives a quantitative estimate of the respondent's current level or depth of psychological dysphoria, thereby summarizing the overall level of psychological distress. For the purposes of the current study, the Global Severity Index (GSI) was used as the primary index of distress.

The BSI also allows researchers to examine T-scores in terms of caseness, which is defined as a GSI T-score ≥ 63 , or two or more subscale scores ≥ 63 . The BSI caseness criteria are generally considered to provide researchers with a good indicator of a positive case, although the SCL-90-R has better developed research regarding caseness on sensitivity and specificity (Derogatis, 1993). Indeed, a number of studies examining adaptation to chronic illness have used caseness criteria for maladaptation with the SCL-90-R (e.g., Mullins et al., 1997; Thompson, Gustafson, Hamlett, & Spock, 1992).

CHAPTER V

ANALYSES

First, preliminary analyses were conducted to provide descriptive statistics for all variables. A correlation matrix between all demographic variables and primary variables of interest was also conducted to look for potential control variables. In addition, a chi-square analysis was conducted to determine if the frequency with which participants met caseness criteria for the BSI differed between the AS and CF groups. Participants met caseness criteria for the BSI if their GSI T-score was equal to or greater than 63 or if two individual subscales had T-scores equal to or greater than 63 (Derogatis, 1993). The BSI caseness criteria serves as a means of defining clinically significant levels of distress, thereby indicating a potential need for intervention. Relevant frequencies are in Table 3 of Appendix F.

Hypothesis 1. The first hypothesis stated that higher mean levels of parental overprotection, parenting stress, and psychological distress would be found in mothers of children with CF compared to mothers of children with asthma. To answer Hypothesis 1, a one-way ANOVA was conducted to examine mean levels of parental overprotection, parenting stress, and psychological distress in mothers of children with asthma compared to mothers of children with CF.

Hypothesis 2. The second hypothesis stated that parental overprotection would be significantly related to psychological distress within each illness group. To answer Hypothesis 2, bi-variate correlation analyses were conducted between parental

overprotection and psychological distress within each group. Partial correlation analyses were also conducted to control for the possible influence of demographic factors, partialling out any demographic variables that were correlated with psychological distress.

Hypothesis 3. The third hypothesis stated that parenting stress would be significantly related to psychological distress within each illness group. To answer Hypothesis 3, bi-variate correlation analyses were conducted between parenting stress and psychological distress within each group. Partial correlation analyses were also conducted to control for the possible influence of demographic factors, partialling out any demographic variables that were correlated with psychological distress.

Hypothesis 4. The fourth hypothesis stated that differential correlational relationships would exist between parental overprotection, parenting stress, and psychological distress within the two illness groups. To answer Hypothesis 4, correlation coefficients for both groups were transformed using the Fisher r -to- Z transformation. The values were then compared to determine whether or not there were significant differences.

Research Question. To address the research question, a hierarchical multiple regression analysis was conducted to assess the independent contribution of parental overprotection, parenting stress, demographics, and illness parameters within the two separate and combined groups. The first step in each hierarchical multiple regression analysis involved a control step, where demographic variables and illness parameters were entered in order to control for the effects of gender, age, and illness

variables. Parental overprotection and parenting stress were then entered on the second step.

CHAPTER VI

RESULTS

Preliminary Analyses

Preliminary analyses were first conducted to provide descriptive statistics for all variables. Please refer to Tables 1 and 2 for means and standard deviations of the variables of interest. Independent samples t-tests indicated no significant mean differences between the two groups on measures of mother's age, child's age, income, education, and the BSI subscales anxiety, depression, and hostility (all p 's > .05). Correlation matrixes between all variables and demographic variables within each separate and combined groups were conducted to look for potential control variables. Please refer to Tables 4, 5 and 6 for correlation matrixes. Within the asthma group, bivariate correlations indicated that psychological distress was significantly correlated with family income and duration of illness ($r = -.238, p < .05$; and $r = .213, p < .05$, respectively). Within the cystic fibrosis group, bivariate correlations indicated that psychological distress was significantly correlated with family income ($r = -.28, p < .05$). Within the combined group, bivariate correlations indicated that psychological distress was significantly correlated with the mother's education level and family income ($r = -.185, p < .05$; and $r = -.262, p < .01$).

Analysis of the results from the *Brief Symptom Inventory* (BSI; Derogatis, 1993) indicated that the rate at which participants met BSI caseness criteria did not differ significantly across the AS and CF groups ($X^2(1, N = 141) = .002, p > .05$).

This suggests that mothers of children with asthma and CF were equally likely to be identified as having a clinically significant level of distress, thereby indicating a potential need for clinical intervention. In the current sample, 36 of the 92 (39.1%) mothers of children with asthma and 19 of the 49 (38.8%) mothers of children with CF met caseness criteria. It should be noted that this rate of meeting caseness criteria across the asthma and CF groups was notably higher than what has been previously found in normative samples. Specifically, normative data suggests that 10% of the population should meet caseness criteria at any given point in time (Derogatis & Spencer, 1982).

Primary Analyses

Hypothesis 1. To answer Hypothesis 1, a one-way ANOVA was conducted to examine mean levels of parental overprotection, parenting stress, and psychological distress in mothers of children with asthma compared to mothers of children with CF. See Table 4 for relevant means and standard deviations. The analyses revealed that the two groups did not differ on the PPS score ($F(1,139) = 1.108, p = .294$), the PSI score ($F(1,139) = 2.092, p = .150$), and the BSI GSI score ($F(1,139) = .089, p = .766$). The results indicate that Hypothesis 1 was not supported.

Hypothesis 2. To answer Hypothesis 2, partial correlation analyses were conducted on parental overprotection and psychological distress within each group. Within the asthma group, correlation analyses between parental overprotection and psychological distress were conducted, partialling out the effects of demographic variables that were correlated with general psychological distress, specifically family income and duration of illness. Parental overprotection remained significantly

correlated with general psychological distress ($r = .215, p = .047$). Within the CF group, after partialling out the effects of the sole demographic variable that was correlated with general psychological distress, specifically family income, parental overprotection was not significantly correlated with general psychological distress ($r = .169, p = .263$). Further analyses within the CF group partialled out the effects of both family income and duration of illness, resulting in parental overprotection not being significantly correlated with general psychological distress ($r = .192, p = .206$). The results indicate that, although parental overprotection was significantly correlated with general psychological distress in the asthma group, it was not significantly correlated with general psychological distress in the CF group.

Hypothesis 3. To answer Hypothesis 3, partial correlation analyses were conducted on parenting stress and psychological distress within each group. Within the asthma group, correlation analyses between parenting stress and general psychological distress were performed, partialling out the effects of demographic variables that were correlated with general psychological distress, specifically family income and duration of illness. Parenting stress remained significantly correlated with general psychological distress ($r = .529, p < .001$). Within the CF group, after partialling out the effects of a demographic variable that was correlated with psychological distress, specifically family income, parenting stress remained significantly correlated with general psychological distress ($r = .610, p < .001$). Further analyses within the CF group partialled out the effects of both family income and duration of illness, resulting in parenting stress still remaining significantly correlated to general psychological distress ($r = .609, p < .001$). Thus, the results

indicate that parenting stress was correlated with general psychological distress in both the asthma and the CF group. Therefore, Hypothesis 3 was supported.

Hypothesis 4. To answer Hypothesis 4, correlation coefficients for both groups were transformed using the Fisher *r*-to-*Z* transformation. Null hypothesis testing for the difference between two correlations revealed that there was no significant difference between parental overprotection and psychological distress ($z = .814, p > .05$), parenting stress and psychological distress ($z = .882, p > .05$), and parental overprotection and parenting stress ($z = .640, p > .05$) for the two groups. The results indicate that Hypothesis 4 was not supported.

Research Question. To address the research question, a hierarchical multiple regression analysis was conducted to assess the independent contribution of demographic variables, illness parameters, parental overprotection and parenting stress to general psychological distress. The first step in the hierarchical multiple regression analysis involved a control step, where demographic variables and illness parameters were entered in order to control for the effects of family income, duration of illness, child's gender, and child's age. Parental overprotection and parenting stress were then entered on the second step. Due to the exploratory nature of these analyses, as well as the non-significant variable mean differences between the two groups, analyses were conducted first with the combined group, then with the two separate groups.

In the combined group, hierarchical regression analyses revealed that, after controlling for mother's education, family income, duration of illness, child's gender, and child's age, parenting stress, but not parental overprotection significantly

predicted general psychological distress, $t(1296) = 7.47, p < .001, b = .562$. The overall model was significant, $F(6,126) = 11.80, p < .001$, accounting for 32.9 % of the variability in psychological distress.

In the asthma group, hierarchical regression analyses revealed that, after controlling for family income, duration of illness, child's gender, and child's age, only parenting stress significantly predicted general psychological distress, $t(82) = 5.74, p < .001, b = .542$. The overall model was significant, $F(5,82) = 8.89, p < .001$, accounting for 31.2 % of the variability in general psychological distress.

In the CF group, hierarchical regression analyses revealed that, after controlling for family income, duration of illness, child's gender, and child's age, only parenting stress significantly predicted general psychological distress, $t(41) = 4.98, p < .001, b = .658$. The overall model was significant, $F(5,41) = 6.35, p < .001$, accounting for 36.8 % of the variability in psychological distress.

CHAPTER V

DISCUSSION

The purpose of the present study was to determine the relationships between parental overprotection, parenting stress, and psychological distress in mothers of children with asthma and mothers of children with cystic fibrosis. Differences in parenting variables both between and within asthma and CF were of particular interest. Further, for exploratory purposes, the study sought to explore the independent contributions of demographic variables, illness parameters, parental overprotection and parenting stress to general psychological distress within the separate and combined groups.

The first hypothesis stated that higher mean levels of parental overprotection, parenting stress, and psychological distress would be found in mothers of children with CF compared to mothers of children with asthma. Results of the analysis revealed that the two groups did not differ on levels of parental overprotection, parenting stress, and general psychological distress, thereby not supporting Hypothesis 1.

Therefore, the results of the first analysis were not consistent with other literature that demonstrates the excessively demanding nature of cystic fibrosis, and the many demands placed on parents compared to other illnesses (Breslau, Staruch, & Mortimer, 1982; Walker, Ford, & Donald, 1987; Mullins et al, 1991; Thompson, Gil, Gustafson, and George, 1994). Certainly, it is possible that the children with CF in

this sample did not manifest sufficient severity to lead to a significant difference in parenting variables between the two illness groups. Certainly, another influencing factor could be the youthfulness of the population. Since parents of young children with CF may not have experienced the consequences of the illness for a long enough duration, their levels of parental overprotection, parenting stress, and general psychological distress might not have increased significantly yet. Future studies should investigate whether the complications experienced by older children with CF are associated with increased levels of parental overprotection, parenting stress, and general psychological distress in their parents.

The second hypothesis stated that parental overprotection would be significantly related to psychological distress within each illness group. Results of the analysis indicated that although parental overprotection was significantly correlated with general psychological distress within the asthma group, it was not significantly correlated with general psychological distress within the CF group, thereby only partially supporting hypothesis 2. This could be explained by several reasons. As mentioned earlier, the children in the CF group may not have been of sufficient illness severity to lead to high levels of overprotection. Also, the relatively small sample size of the CF group may have resulted in a significant correlation between parental overprotection and general psychological distress not being detected. Given the limited sample size, the power of the study may have diminished. It is clear that, particularly in the case of the CF group, power is an important issue. Although no significant mean differences in parental overprotection, parenting stress, and psychological distress between mothers of children with asthma and mothers of

children with CF were found, this discernible difference between the two disease groups when using disease-specific analyses indicated that there can be differential patterns within each disease state. According to Mullins, et al. (1995), a disease-specific or categorical approach yields important clinical information which ultimately can be translated into intervention strategies. This investigation suggests that, although both asthma and CF are pulmonary diseases, different processes of adaptation may occur within each group.

The third hypothesis stated that parenting stress would be significantly related to psychological distress within each illness group. Results of the analysis indicated that parenting stress was indeed correlated with general psychological distress in both the asthma and the CF group, thereby supporting hypothesis 3. Thus, unlike parental overprotection, it would seem that parenting stress is a significant corollary of general psychological distress across both illness groups. This suggests that both disease groups demonstrate a strong relationship between parenting stress and general psychological distress. However, this does not indicate that parenting stress necessarily leads to general psychological distress. Instead, it is likely that there is a bidirectional relationship between parenting stress and general psychological distress. These results reveal the importance of targeting parenting stress when developing interventions aimed at mothers of children with asthma and mothers of children with CF.

The fourth hypothesis stated that differential correlational relationships would exist between parental overprotection, parenting stress, and psychological distress within the two illness groups. The results indicated that there were no

significant differences between parental overprotection and psychological distress, parenting stress and psychological distress, and parental overprotection and parenting stress, for the two groups. Therefore hypothesis 4 was not supported. It is possible that the low sample size of the CF group may not have allowed for significant differences in correlations to be detected. It is also possible, however, that the two disease groups may not be dissimilar enough to cause significant differences in correlations between the variables of interest.

The exploratory research question was aimed at exploring the independent contributions of parental overprotection, parenting stress, illness parameters, and demographic parameters to psychological distress within the combined and separate groups. Results of the analyses indicated that, in the combined group, after controlling for family income, duration of illness, child's gender, and child's age, parenting stress significantly predicted general psychological distress. The overall model was significant and accounted for 33.2 % of the variability in psychological distress.

Results of the analysis in the asthma group indicated that, after controlling for family income, duration of illness, child's gender, and child's age, only parenting stress significantly predicted general psychological distress. The overall model was significant and accounted for 31.2 % of the variability in general psychological distress.

Results of the analysis in the CF group indicated that, after controlling for family income, duration of illness, child's gender, and child's age, only parenting stress significantly predicted general psychological distress. The overall model was

significant and accounted for 36.8 % of the variability in psychological distress. In sum, it is apparent that parenting stress is a significant and robust predictor of general psychological distress in mothers of children with asthma and CF. Although parental overprotection was significantly correlated with general psychological distress in the asthma group, it would appear to be a less salient or weaker predictor of general psychological distress when evaluated in the presence of parenting stress. Future studies should attempt to replicate these findings with larger sample sizes.

Strength and Limitations

Several strengths of the current study are notable. First, the present study sought to investigate and compare parents of children with two different chronic illnesses across parenting variables and general psychological distress. The median life expectancy for individuals with CF has increased dramatically in the last two decades and is currently estimated to be about 40 years (Elborn, Shale, & Britton, 1992; Kulich, Rosenfeld, Goss, & Wilmott, 2003). This has resulted in parents of children with CF living with their child's illness for much longer, thereby presenting them with a more enduring stressor. However, to date, there has been no other research conducted on families of children with asthma or CF to document levels of overprotection and parenting stress. Thus, the present study represents a unique effort to document how parental overprotection and parenting stress relate to general psychological distress in parents of children with asthma and parents of children with CF. Directly comparing the two groups in terms of these variables provides valuable knowledge and contributes to the development of comparative studies in the future.

Second, the current study incorporates a disease-specific approach in its analyses of parenting variables in chronic illness populations. Studying the asthma and CF groups separately and in combined fashion enables us to examine variable relationships that may be relatively unique to a particular disease group.

Several important limitations are acknowledged in the current study. First, the cross-sectional design limits any causal inferences that can be made. Thus, although an apparent relationship between parenting stress and general psychological distress exists in both parents of children with asthma and CF, inferences about causation and direction cannot reliably be made. Thus, future research may implement a longitudinal design that would track and compare the changes that individuals with different chronic illnesses and their parents encounter across a span of several years or possibly decades.

Second, due to the relatively small sample size of the CF group within the context of statistical analyses, it is possible that significant differences between the two chronic illness groups were not detected. The sample size may have resulted in a larger standard error and weak power. Although the relatively low incidence of the illnesses, CF in particular, makes it difficult to obtain large sample sizes, future research may need to include larger samples so as to increase power, ensure the detection of any differences, and to more closely approximate the population.

Third, while the results of the study can, to be generalized to mothers of children with asthma or mothers of children with CF, they cannot be generalized to fathers of children with these chronic illnesses. Indeed, there is a lack of research concerning how fathers of children with these two chronic illnesses cope, and how

parenting variables such as parental overprotection and parenting stress influence general psychological distress. Future studies will need to investigate fathers, as not only might there be differing patterns between mothers of children with different chronic illnesses, but there may also be differences between mothers and fathers within the same chronic illness. As the role of the father in modern society has become more salient and influential, with father's becoming more involved and sometimes reversing roles with the mother, it is important to investigate parenting variables and general psychological distress in both parents. Differences between mothers and fathers may even result in the development of gender-specific interventions.

Conclusions and Future Directions

Overall, the present study found support for a number of its hypotheses related to parental overprotection, parenting stress, and general psychological distress in mothers of children with asthma and mothers of children with CF. The current study found that, although there were no significant mean differences in parental overprotection, parenting stress, and psychological distress between the two illness groups, parental overprotection was significantly correlated with general psychological distress within the asthma group, but not the CF group. Consequently, interventions aimed at parents of children with asthma may address general psychological distress vis a vis the construct of parental overprotection. Indeed, the evidence that different correlations emerged *within* the group further supports the notion that, when planning interventions for individuals with a chronic illness or parents of children with a chronic illness, disease-specific approaches need to be

taken. Arguably, the limited number of participants in the CF group may have influenced power, and hence the ability to detect differences between the two groups. Future research may need to focus on recruiting a larger and possibly more severely impaired sample of parents of children with asthma and parents of children with CF in order to more effectively test the hypotheses presented in the current study.

The study's results indicated that parenting stress was significantly correlated with general psychological distress in both illness groups, accounting for a large portion of the variability in general psychological distress. The need for future research to focus specifically on parenting stress in the context of the chronically ill child is paramount. Advances in technology and medication have resulted in the increased longevity of many chronic illnesses, CF in particular, thereby affecting the nature of the parent-child relationship. In other words, research on parenting stress may serve to guide the development of more effective disease-specific interventions.

Irrespective of the form in which future research is carried out, continued research with parents of children with chronic illnesses, and the children themselves, is important in order to document the different processes of adaptation that occur in populations with different chronic illnesses.

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APPENDICES

APPENDIX A
BACKGROUND INFORMATION QUESTIONNAIRE

Background Information

Today's Date _____

Subject No. _____

- 1. Child's Name: _____ Age: _____
- 2. Mother's Name: _____ Age: _____
- 3. Father's Name: _____ Age: _____
- 4. Name of person filling out this form and relationship to child (e.g., mother): _____

5. Who currently lives in the household with you and your child? Please note their relationship to the child and age (e.g., brother-15 months, stepparent - 36 yrs old).

Name	Relation to child	Age
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

6. Telephone number: _____

7. Child's Gender: Male 1 Female 2

8. Child's Race: Caucasian 1 African-American 2 Hispanic 3 Native American 4 Other: _____ 5

9. Child's Grade _____

10. Special Education Yes _____ No _____

11. Parents' Marital Status: Married 1 Single Parent 2 Remarried 3 Never Married 4 Other 5

12. Parents' Occupations: Father _____ Mother _____

13. Parents' Highest Level of Education: Father _____ Mother _____

14. Please indicate your total family income: _____ 0-4,999 _____ 30,000-39,999
 (This information will be held _____ 5,000-9,999 _____ 40,000-49,999
 strictly confidential). _____ 10,000-14,999 _____ 50,000-59,000
 _____ 15,000-19,999 _____ 60,000 or greater
 _____ 20,000-29,999

APPENDIX B
HEALTH CARE UTILIZATION QUESTIONNAIRE

HCUQ

1. Please indicate the number of outpatient clinic visits your child scheduled and attended in the last year. _____
2. Please indicate the number of hospitalizations for your child the past year that were directly or indirectly related to their illness. _____
3. If your child was hospitalized, please indicate the total number of days spent as an inpatient in the past year. _____
4. Please indicate how many visits your child made to the emergency room in the past year due to problems with their illness. _____
5. How do you pay for your child's medical care and medical supplies?
A) Insurance _____ D) Self-Pay _____
B) HMO/PPO _____ E) Other _____
C) Medicaid _____
6. Please estimate the dollars per month you spent this year on health insurance premiums.
\$ _____ per/month.
7. Please estimate the dollars per month you spent this last year on out-of-pocket expenses for the care of your child's illness. \$ _____ per/month.
8. How many hours a month do you spend working with insurance companies, hospitals, medicaid, etc. about financial aspects of your child's illness? _____
- 9a. Insurance/HMO/PPO beneficiaries: Do you stay in your current employment situation because of concern over obtaining new health benefits?
Yes No
- 9b. Medicaid beneficiaries: Do you stay in your current living situation to keep medicaid benefits?
Yes No
10. Are you concerned that your child will have difficulty obtaining health benefits when they are adults?
Yes No
11. How much do you worry about financial stress placed on the family because of your child's illness?
1 2 3 4 5 6 7
not worried *moderately worried* *constantly worried*

APPENDIX C
PARENT PROTECTION SCALE

PBS/CVE

Thomasgard, Shonkoff, Metz & Edalbrock

Please read each statement carefully and determine the extent to which the statement is descriptive of your behavior with your child.

	Never (0)	Sometimes (1)	Most of the time (2)	Always (3)
1. I blame myself when my child gets hurt.....	0	1	2	3
2. I comfort my child immediately when he/she cries.....	0	1	2	3
3. I encourage my child to depend on me.....	0	1	2	3
4. I have difficulty separating from my child.....	0	1	2	3
5. I trust my child on his/her own.....	0	1	2	3
6. I let my child make his/her own decisions.....	0	1	2	3
7. I have difficulty leaving my child with a babysitter.....	0	1	2	3
8. I decide when my child eats.....	0	1	2	3
9. I use baby words when I talk to my child.....	0	1	2	3
10. I urge my child to try new things.....	0	1	2	3
11. I determine who my child will play with.....	0	1	2	3
12. I keep a close watch on my child.....	0	1	2	3
13. I feed my child even if he/she can do it alone....	0	1	2	3
14. I feel comfortable leaving my child with other people.....	0	1	2	3
15. I protect my child from criticism.....	0	1	2	3
16. I let my child choose what he/she wears.....	0	1	2	3
17. I make my child go to sleep at a set time.....	0	1	2	3
18. I go to my child if he/she cries during the night.....	0	1	2	3
19. I encourage my child to play with other children..	0	1	2	3
20. I give my child extra attention when he/she clings to me.....	0	1	2	3

Never (0) Sometimes (1) Most of the time (2) Always (3)

- 21. I decide what my child eats.....0 1 2 3
- 22. I dress my child even if he/she can do it alone...0 1 2 3
- 23. I decide when my child goes to the bathroom.....0 1 2 3
- 24. I know exactly what my child is doing.....0 1 2 3
- 25. I allow my child to do things on his/her own.....0 1 2 3

-
- 1. In general my child seems less healthy than other children.....0 1 2 3
 - 2. I often think about calling the doctor about my child.....0 1 2 3
 - 3. When there is something going around, my child usually catches it.....0 1 2 3
 - 4. I sometimes get concerned that my child doesn't look as healthy as s/he should.....0 1 2 3
 - 5. I often have to keep my child indoors because of health reasons.....0 1 2 3
 - 6. My child gets more colds than other children I know.....0 1 2 3
 - 7. I get concerned about circles under my child's eyes.....0 1 2 3
 - 8. I often check on my child at night to make sure that s/he is okay.....0 1 2 3

APPENDIX D
PARENTING STRESS INDEX – SHORT FORM

PARENTING STRESS INDEX

(Short Form)

Richard R. Abidin
University of Virginia

Directions:

In answering the following questions, please think about the child you are most concerned about.

The questions on the following pages ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by circling the number which best matches how you feel. If you are not sure, please circle #3.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

Example:

I enjoy going to the movies. (If you sometimes enjoy going to the movies, you would circle #2.)

1 ② 3 4 5

1 Strongly Agree 2 Agree 3 Not Sure 4 Disagree 5 Strongly Disagree

1. I often have the feeling that I cannot handle things very well. 1 2 3 4 5
2. I find myself giving up more of my life to meet my children's needs than I ever expected. 1 2 3 4 5
3. I feel trapped by my responsibilities as a parent. 1 2 3 4 5
4. Since having this child I have been unable to do new and different things. 1 2 3 4 5
5. Since having a child I feel that I am almost never able to do things that I like to do. 1 2 3 4 5
6. I am unhappy with the last purchase of clothing I made for myself. 1 2 3 4 5
7. There are quite a few things that bother me about my life. 1 2 3 4 5
8. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend). 2 3 4 5
9. I feel alone and without friends. 2 3 4 5
10. When I go to a party I usually expect not to enjoy myself. 2 3 4 5
11. I am not as interested in people as I used to be. 2 3 4 5
12. I don't enjoy things as I used to. 2 3 4 5
13. My child rarely does things for me that make me feel good. PD 2 3 4 5
14. Most times I feel that my child does not like me and does not want to be close to me. 1 2 3 4 5
15. My child smiles at me much less than I expected. 1 2 3 4 5
16. When I do things for my child I get the feeling that my efforts are not appreciated very much. 1 2 3 4 5
17. When playing, my child doesn't often giggle or laugh. 1 2 3 4 5
18. My child doesn't seem to learn as quickly as most children. 1 2 3 4 5
19. My child doesn't seem to smile as much as most children. 1 2 3 4 5
20. My child is not able to do as much as I expected. 1 2 3 4 5
21. It takes a long time and it is very hard for my child to get used to new things. 1 2 3 4 5

APPENDIX E
BRIEF SYMPTOM INVENTORY

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	(1)	(2)	(3)	(4)	(5)	Nervousness or shakiness inside
2	(1)	(2)	(3)	(4)	(5)	Faintness or dizziness
3	(1)	(2)	(3)	(4)	(5)	The idea that someone else can control your thoughts
4	(1)	(2)	(3)	(4)	(5)	Feeling others are to blame for most of your troubles
5	(1)	(2)	(3)	(4)	(5)	Trouble remembering things
6	(1)	(2)	(3)	(4)	(5)	Feeling easily annoyed or irritated
7	(1)	(2)	(3)	(4)	(5)	Pains in heart or chest
8	(1)	(2)	(3)	(4)	(5)	Feeling afraid in open spaces or on the streets
9	(1)	(2)	(3)	(4)	(5)	Thoughts of ending your life
10	(1)	(2)	(3)	(4)	(5)	Feeling that most people cannot be trusted
11	(1)	(2)	(3)	(4)	(5)	Poor appetite
12	(1)	(2)	(3)	(4)	(5)	Suddenly scared for no reason
13	(1)	(2)	(3)	(4)	(5)	Temper outbursts that you could not control
14	(1)	(2)	(3)	(4)	(5)	Feeling lonely even when you are with people
15	(1)	(2)	(3)	(4)	(5)	Feeling blocked in getting things done
16	(1)	(2)	(3)	(4)	(5)	Feeling lonely
17	(1)	(2)	(3)	(4)	(5)	Feeling blue
18	(1)	(2)	(3)	(4)	(5)	Feeling no interest in things
19	(1)	(2)	(3)	(4)	(5)	Feeling fearful
20	(1)	(2)	(3)	(4)	(5)	Your feelings being easily hurt
21	(1)	(2)	(3)	(4)	(5)	Feeling that people are unfriendly or dislike you
22	(1)	(2)	(3)	(4)	(5)	Feeling inferior to others
23	(1)	(2)	(3)	(4)	(5)	Nausea or upset stomach
24	(1)	(2)	(3)	(4)	(5)	Feeling that you are watched or talked about by others
25	(1)	(2)	(3)	(4)	(5)	Trouble falling asleep
26	(1)	(2)	(3)	(4)	(5)	Having to check and double-check what you do
27	(1)	(2)	(3)	(4)	(5)	Difficulty making decisions
28	(1)	(2)	(3)	(4)	(5)	Feeling afraid to travel on buses, subways, or trains
29	(1)	(2)	(3)	(4)	(5)	Trouble getting your breath
30	(1)	(2)	(3)	(4)	(5)	Hot or cold spells
31	(1)	(2)	(3)	(4)	(5)	Having to avoid certain things, places, or activities because they frighten you
32	(1)	(2)	(3)	(4)	(5)	Your mind going blank
33	(1)	(2)	(3)	(4)	(5)	Numbness or tingling in parts of your body
34	(1)	(2)	(3)	(4)	(5)	The idea that you should be punished for your sins
35	(1)	(2)	(3)	(4)	(5)	Feeling hopeless about the future
36	(1)	(2)	(3)	(4)	(5)	Trouble concentrating
37	(1)	(2)	(3)	(4)	(5)	Feeling weak in parts of your body
38	(1)	(2)	(3)	(4)	(5)	Feeling tense or keyed up
39	(1)	(2)	(3)	(4)	(5)	Thoughts of death or dying
40	(1)	(2)	(3)	(4)	(5)	Having urges to beat, injure, or harm someone
41	(1)	(2)	(3)	(4)	(5)	Having urges to break or smash things
42	(1)	(2)	(3)	(4)	(5)	Feeling very self-conscious with others
43	(1)	(2)	(3)	(4)	(5)	Feeling uneasy in crowds, such as shopping or at a movie
44	(1)	(2)	(3)	(4)	(5)	Never feeling close to another person
45	(1)	(2)	(3)	(4)	(5)	Spells of terror or panic
46	(1)	(2)	(3)	(4)	(5)	Getting into frequent arguments
47	(1)	(2)	(3)	(4)	(5)	Feeling nervous when you are left alone
48	(1)	(2)	(3)	(4)	(5)	Others not giving you proper credit for your achievements
49	(1)	(2)	(3)	(4)	(5)	Feeling so restless you couldn't sit still
50	(1)	(2)	(3)	(4)	(5)	Feelings of worthlessness
51	(1)	(2)	(3)	(4)	(5)	Feeling that people will take advantage of you if you let them
52	(1)	(2)	(3)	(4)	(5)	Feelings of guilt
53	(1)	(2)	(3)	(4)	(5)	The idea that something is wrong with your mind

APPENDIX F
RELEVANT RESULTS

Table 1

Means and Standard Deviations by Illness Group

	Asthma		Cystic Fibrosis	
	M	SD	M	SD
Parental Overprotection	28.40	6.57	29.69	7.58
Parenting Stress	76.54	20.89	71.18	21.05
Psychological Distress	54.30	10.67	54.90	12.21
Child's Age	10.02	3.64	9.98	4.78
Mother's Age	38.90	5.87	37.46	6.68
Mother's Education Level (Years)	14.96	2.43	14.26	2.10
Family Income Category	6.83	2.36	6.23	2.73
Duration of Illness (Years)	7.73	3.85	8.76	5.13

Table 2

Marital Status Percentages by Illness Group

Marital Status	Asthma	Cystic Fibrosis
Married	79.3%	71.4%
Single	10.9%	10.2%
Remarried	5.4%	6.1%
Never Married	1.1%	2.0%
Other	1.1%	10.2%

Table 3

Frequency of BSI Caseness Classification for AS and CF Participants

BSI Caseness	Asthma	Cystic Fibrosis
Met caseness	36 (39.1%)	19 (38.8%)
Did not meet caseness	56 (60.9%)	30 (61.2%)
N	92	49

Table 4

Bivariate Correlations – Asthma

	Child's Age	Mother's Age	Mother's Education Level	Family Income	Duration of Illness in Years	PPS Total Score	PSI Total Score	BSI GSI
Child's Age	-	.486**	-.120	-.058	.840**	-.460**	.004	.139
Mother's Age		-	.271**	.262*	.388**	-.200	-.035	-.047
Mother's Education Level			-	.554**	-.102	-.208*	-.186	-.199
Family Income				-	-.052	-.185	-.265*	-.238*
Duration of Illness in Years					-	-.404**	.041	.213*
PPS Total Score						-	.277**	.129
PSI Total Score							-	.555**
BSI GSI								-

PPS = Parent Protection Scale; PSI = Parenting Stress Index; BSI GSI = Brief Symptom Inventory – General Stress Index; * = $p \leq .05$; ** = $p \leq .01$.

Table 5

Bivariate Correlations – CF

	Child's Age	Mother's Age	Mother's Education Level	Family Income	Duration of Illness in Years	PPS Total Score	PSI Total Score	BSI GSI
Child's Age	-	.629**	.081	-.071	.855**	-.498**	.081	.022
Mother's Age		-	.232	.123	.447**	-.594**	-.099	-.042
Mother's Education Level			-	.594**	.156	-.325*	-.176	-.164
Family Income				-	-.057	-.342*	-.406**	-.288**
Duration of Illness in Years					-	-.494**	.001	-.010
PPS Total Score						-	.379**	.268
PSI Total Score							-	.654**
BSI GSI								-

PPS = Parent Protection Scale; PSI = Parenting Stress Index; BSI GSI = Brief Symptom Inventory – General Stress Index; * = $p \leq .05$; ** = $p \leq .01$.

Table 6

Bivariate Correlations – Asthma and CF combined

	Child's Age	Mother's Age	Mother's Education Level	Family Income	Duration of Illness in Years	PPS Total Score	PSI Total Score	BSI GSI
Child's Age	-	.546**	-.044	-.060	.840**	-.474**	.036	.087
Mother's Age		-	.266**	.217*	.395**	-.368**	-.045	-.048
Mother's Education Level			-	.568**	-.022	-.251**	-.158	-.185*
Family Income				-	-.065	-.259**	-.299**	-.262**
Duration of Illness in Years					-	-.429**	.010	.116
PPS Total Score						-	.301**	.187*
PSI Total Score							-	.584**
BSI GSI								-

Table 7

One-way ANOVA

Source	SS	<i>df</i>	MS	F	<i>p</i>
PPSTOT					
Between Groups	53.345	1	53.345	1.108	.294
Within Groups	6690.528	139	48.133		
Total	6743.872	140			
PSITOT					
Between Groups	918.465	1	918.465	2.092	.150
Within Groups	61034.173	139	439.095		
Total	61952.638	140			
BSI GSI					
Between Groups	11.266	1	11.266	.089	.766
Within Groups	17537.968	139	126.172		
Total	17549.234	140			

Table 8

Asthma - Partial Correlations Between Parental Overprotection (PPS) and General Psychological Distress (BSI GSI), Controlling for Family Income and Duration of Illness

	BSI GSI
PPS	
<i>r</i>	.215*
<i>p</i>	.047
<i>df</i>	0,84

PPS = Parent Protection Scale; * = $p \leq .05$.

Table 9

Asthma - Partial Correlations Between Parenting Stress (PSI) and General Psychological Distress (BSI GSI), Controlling for Family Income and Duration of Illness

	BSI GSI
PSI	
<i>r</i>	.529**
<i>p</i>	.000
<i>df</i>	0,84

PSI = Parenting Stress Index; ** = $p \leq .01$.

Table 10

CF - Partial Correlations Between Parental Overprotection (PPS) and General Psychological Distress (BSI GSI), Controlling for Family Income only

	BSI GSI
PPS	
<i>r</i>	.169
<i>p</i>	.263
<i>df</i>	0,44

PPS = Parent Protection Scale

Table 11

CF - Partial Correlations Between Parenting Stress (PSI) and General Psychological Distress (BSI GSI), Controlling for Family Income only

	BSI GSI
PSI	
<i>r</i>	.610**
<i>p</i>	.000
<i>df</i>	0,44

PSI = Parenting Stress Index; ** = $p \leq .01$.

Table 12

CF - Partial Correlations Between Parental Overprotection (PPS) and General Psychological Distress (BSI GSI), Controlling for Family Income and Duration of Illness

	BSI GSI
PPS	
<i>r</i>	.192
<i>p</i>	.206
<i>df</i>	0,43

PPS = Parent Protection Scale

Table 13

CF - Partial Correlations Between Parenting Stress (PSI) and General Psychological Distress (BSI GSI), Controlling for Family Income and Duration of Illness

	BSI GSI
PSI	
<i>r</i>	.609**
<i>p</i>	.000
<i>df</i>	0,43

PSI = Parenting Stress Index; ** = $p \leq .01$.

Table 14

Summary of Hierarchical Regression Analysis for Variables Predicting Psychological Distress

Step	Variable	Beta	R ²	F	df
Predicting Psychological Distress among Parents of Children with Asthma and CF (N = 141).					
1	Mother's Education	-.069	.076	2.093	(5,127)
	Family Income	-.202			
	Illness Duration	.090			
	Child's Gender	-.003			
	Child's Age	.019			
2	Mother's Education	-.074	.360	11.806	(6,126)
	Family Income	-.045			
	Illness Duration	.158			
	Child's Gender	-.080			
	Child's Age	-.045			
	PSI Total	.562***			

Note: Parental Overprotection was excluded from the equation.

Predicting Psychological Distress among Parents of Children with Asthma (N = 92).

1	Family Income	-.215*	.091	2.078	(4,83)
	Illness Duration	.280			
	Child's Gender	.013			
	Child's Age	-.103			
2	Family Income	-.082	.352	8.895	(5,82)
	Illness Duration	.211			
	Child's Gender	-.095			
	Child's Age	-.025			
	PSI Total	.542***			

Note: Parental Overprotection was excluded from the equation.

Predicting Psychological Distress among Parents of Children with CF (N = 49).

1	Family Income	-.285	.095	1.099	(4,42)
	Illness Duration	-.188			
	Child's Gender	-.004			
	Child's Age	.206			
2	Family Income	-.024	.437	6.356	(5,41)
	Illness Duration	.020			
	Child's Gender	-.116			
	Child's Age	.000			
	PSI Total	.658***			

Note: Parental Overprotection was excluded from the equation.

PSI = Parenting Stress Index; * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

VITA

Leafar F-J Espinoza

Candidate for the Degree of

Master of Science

Thesis: THE RELATIONSHIP OF PARENTAL OVERPROTECTION AND PARENTING STRESS TO PSYCHOLOGICAL DISTRESS IN PARENTS OF CHILDREN WITH ASTHMA AND CYSTIC FIBROSIS: A CROSS ILLNESS COMPARISON

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A relatively unexplored area in the literature concerns how specific parental psychological variables, such as parental overprotection and parenting stress, are associated with psychological distress in different illness groups. This study examines the relationships between parental overprotection, parenting stress, and psychological distress in parents of children with asthma and parents of children with cystic fibrosis. Differences in parenting variables both between and within asthma and CF groups are of particular interest. The study's results indicate that parenting stress is significantly correlated with general psychological distress in both illness groups, accounting for a large portion of the variability in general psychological distress. The need for future research to focus specifically on parenting stress in the context of the chronically ill child is paramount. In other words, research on parenting stress may serve to guide the development of more effective disease-specific interventions.

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