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The Association of Depression and Stigma in Caregivers of Children with Cystic Fibrosis

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Abstract

The Association of Depression and Stigma in Caregivers of Children with Cystic Fibrosis By Mary Danielle Kuykendall

The purpose of this research survey was to investigate the relationship between depression and perceived stigma in caregivers of children with cystic fibrosis (CF). Several studies have shown that caregivers of children with CF are at an increased risk for depression. Additionally, perceived stigma has been shown to be associated with this population. Theory of Reasoned Action was used to investigate how social norms (i.e., stigma) can influence attitudes (i.e., depression) as high perceived stigma combined with high levels of depression can lead to increased caregiver strain, decreasing caregivers' desire to carry out behavioral intentions or behaviors, such as seeking treatment for their depression, or fulfilling their roles as caregivers. Thirty-five caregivers of children with CF completed a short survey. The presence and severity of depressive symptoms was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) and the Parent Stigma Scale was used to measure stigma. Results show that with increased depressive symptoms in caregivers, perceived stigma also increased. In a linear regression model, perceived stigma was significantly associated with depressive symptoms when sex was controlled. Additionally, males were found to have higher depression scores compared to females when perceived stigma scores were controlled. Recommendations include regular screening for depressive symptoms in caregivers as levels are often seen above population norm. Also, primary care providers are recommended to assess perceived stigma in caregivers in order to connect those who do feel stigmatized to additional resources to help combat the stigma and/or cope with their feelings.

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Chapter I. Introduction

Cystic Fibrosis (CF), the most frequent, fatal, genetic disease among Caucasians (Sheppard & Nicholson, 2002), is a chronic disease that is often diagnosed early in life. Rigorous at-home therapies, as well as numerous medical appointments, characterize the treatments of the disease. Caregivers, such as parents, guardians, siblings, or relatives, are integral to the management of these treatments for those affected. Time commitment and complexity of treatments, guilt of passing on a genetic disease, marital role strain, the shortened life expectancy of the child with CF, among other things, contribute to the caregiver strain that is often seen (Driscoll, Montag-Leifling, Acton, & Modi, 2009).

Caregiver role strain has been associated with increased depression among this population (Driscoll et al., 2009). Depression is a serious public health concern today as 16.6% of the United States population experience major depressive disorder in their lifetimes, and 6.7% in a 12 month period (R. C. Kessler, Berglund, et al., 2005; R. C. Kessler, Chiu, Demler, Merikangas, & Walters, 2005). Unfortunately, only 51.7% of those with major depressive disorder are currently receiving treatment (Wang et al., 2005).

In addition to role strain and depression, caregivers can also experience stigma. Stigma is associated with many different chronic health conditions and leads to suffering and distress of those who are stigmatized (Jacoby, Gorry, Gamble, & Baker, 2004). Stigma not only affects the chronically ill person, however, it also affects those who are closely associated with the ill person; this is referred to as courtesy stigma (Goffman, 1963). When one perceives this stigma directed toward them, it can become an obstacle to seeking care. In the role of a parent caregiver of a child with a genetic illness, a

courtesy stigma is sometimes bestowed upon that person and can result in negative coping mechanisms (Markowitz, 1998). Genetics disorders have been linked to courtesy stigma throughout history. When mental illness became linked to genetics, there was thought that those who are biologically related to the person with a mental illness may experience a courtesy stigma. Likewise, epilepsy has also held concern of “courtesy” stigma due to its genetic nature (Shostak, Zarhin, & Ottman, 2011).

It is important to determine whether depression and perceived stigma are associated in caregivers of youth with CF. If they are, perceived stigma may be a barrier to caregivers’ receiving care for depression. Furthermore, CF treatment is rigorous, comprehensive and time consuming (A.D.A.M. Medical Encyclopedia, 2012), and the added strain on caregivers of stigma and depression combined, can have a negative impact on the care a child with CF receives.

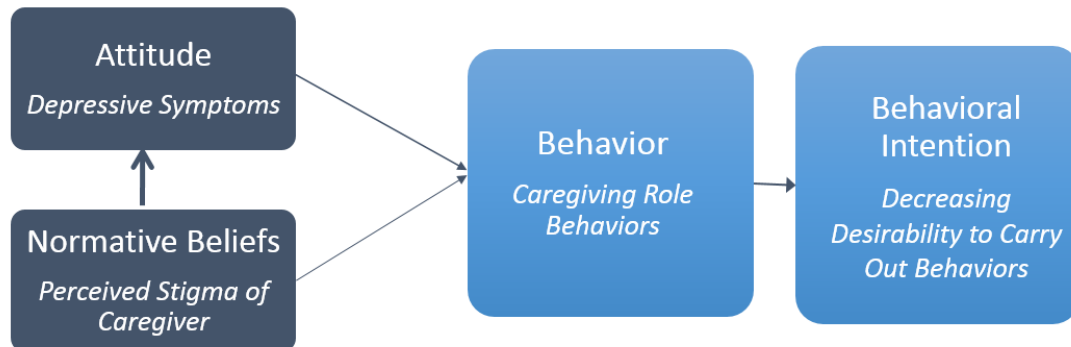
Theory of Reasoned Action

The Theory of Reasoned Action (TRA) is a model of individual behavior. TRA was developed by Martin Fishbein and Icek Ajzen (1975) to understand the relationships between attitudes, intentions and behaviors. According to TRA, behavioral intention, or an individual’s readiness to perform a given behavior, is the primary predictor of behavior. Behavioral intention is predicted by the combination of attitude toward and social normative perceptions of the behavior (Fishbein & Ajzen, 1975). More recently, researchers have begun to recognize that normative beliefs influence not only behavioral intention and behavior, but attitudes, as well (Terry & Hogg, 1996). Attitude toward a behavior comes from one’s behavioral belief, or beliefs about the outcomes associated with performing that behavior. A strong positive behavioral belief will result in a strong

attitude toward performing that behavior while a strong negative behavior belief about the outcome will result in a strong negative attitude toward the behavior. Subjective norm is determined by the normative belief and motivation to comply with that belief. Normative belief is how a person believes others' perceptions are surrounding that behavior. When attitudes and subjective norms are taken into account, intention to perform the behavior is determined. This directly influences the likelihood that one will carry out the behavior (Glanz, Rimer, & Viswanath, 2008).

Social normative perceptions combined with attitude can be used to explain the association between stigma and depression in caregivers of those with CF as the negative outcomes associated with stigma and depression can predict behaviors associated with care-giver burden and role strain (Glanz et al., 2008). More specifically, perceived stigma is an indicator of normative beliefs, since stigma is based upon "socially conferred judgment" (Pescosolido, Martin, Lang, & Olafsdottir, 2008). Likewise, depression is an indicator of attitudes, since attitudes have been related to depression in several studies (Alloy et al., 1999; Sherry et al., 2012). According to theory and past research, then, social norms (i.e., stigma) can influence attitudes (i.e., depression) (Figure 1). Furthermore, high perceived stigma combined with high levels of depression can lead to increased caregiver strain, decreasing caregivers' desire to carry out behavioral intentions or behaviors, such as seeking treatment for their depression, or fulfilling their roles as caregivers. This study explores the association of stigma and depression in caregivers of those with a genetic disease. With results from this preliminary study, further research can investigate how to change these normative beliefs.

Figure 1. TRA Model



Purpose

The purpose of this research survey was to investigate the relationship between depression and perceived stigma in caregivers of children with cystic fibrosis. As stigmatization of CF for caregivers and depression in CF caregivers have both been shown through research to be of concern for this community, the association between stigma and depression in caregivers warranted research. The research questions were the following:

Q1. Are levels of perceived stigma associated with level of depressive symptoms among caregivers of children with cystic fibrosis?

Q2. Are levels of perceived stigma associated with levels of depressive symptoms among caregivers of children with cystic fibrosis when gender of the caregiver, age of the caregiver, relationship to the child, caregiver's marital status, number of children, child's age, and duration of child's diagnosis are controlled?

Chapter II. Review of the Literature

The purpose of this research study was to investigate the relationship between depression and stigma in caregivers of children with cystic fibrosis. To further investigate this research question, the topics of cystic fibrosis, stigma, depression, and caregivers were investigated. The literature review outlines the aforementioned topics, as well as describes the known relationships among them. These links tie together in the end to validate the need for investigation into the possible relationship between depression and stigma in caregivers of children with cystic fibrosis.

Cystic Fibrosis

Background

Cystic Fibrosis (CF) is an incurable chronic disease of autosomal, recessive origin. It affects mucus production of exocrine glands, which then becomes thick and obstructs secretion channels (Pizzignacco, de Mello, & de Lima, 2010). Abnormally thick mucus is produced, which accumulates in the lungs and the pancreas. As the sticky mucus accumulates, it can result in life-threatening lung infections as well as digestion problems. Sweat glands and the male reproductive system are also sometimes affected. In newborns, CF is characterized by delayed growth, failure to gain weight normally, salty-tasting skin, and a lack of bowel movements in the first 24 to 48 hours of life. Later life symptoms include infertility in men, pancreatitis, and respiratory symptoms. Typical symptoms that affect the lungs and sinuses include: coughing, increased mucus in the sinuses or lungs, fatigue, nasal congestion related to nasal polyps, recurrent pneumonia, and sinus pain or pressure caused by infection or polyps. Pneumonia in someone with CF would show fever, increased coughing, increased shortness of breath, loss of appetite, and

more sputum. Pancreatic symptoms would show as belly pain related to severe constipation, increased gas, bloating or belly distention, nausea, loss of appetite, pale or clay-color stools, foul smelling stools, stools with mucus or floating stools, and weight loss (A.D.A.M. Medical Encyclopedia, 2012).

Who CF affects

The defective gene that causes CF is carried by millions of Americans, 1 in every 29 Caucasian Americans. However, most CF gene carriers do not have symptoms, as someone with CF has to inherit the gene from both parents to develop disease (A.D.A.M. Medical Encyclopedia, 2012). CF is most common among Caucasians and affects 1:2,500 Europeans (Pizzignacco et al., 2010); it is the most common and deadly inherited disorder in the United States that affects Caucasians, especially in those of Northern or Central European descent (A.D.A.M. Medical Encyclopedia, 2012).

Diagnosis

CF is typically diagnosed by age two. Rare individuals are not diagnosed until they are 18 years or older, and these typically have a milder form of CF. There is no way to prevent CF, so screening children with family history to detect the gene is the primary means of early detection. The standard diagnostic test for CF is the sweat chloride test, which looks for a high salt level in a patient's sweat, as this is a sign of the disease. Diagnosis of CF can be also made through a blood test to detect the CF gene that causes the disease. Another test, immunoreactive trypsinogen (IRT), is used to screen newborns. This standard test shows IRT levels, with elevated levels suggesting CF (A.D.A.M. Medical Encyclopedia, 2012). Additional tests that are often run to identify problems related to CF include: chest x-ray or CT scans, fecal fat tests, lung function tests,

measurement of pancreatic function, secretin stimulation test, trypsin and chymotrypsin in stool, upper GI and small bowel series (A.D.A.M. Medical Encyclopedia, 2012).

Treatment

CF requires several treatments a day, many of which can now be done at home to allow people to perform normal daily tasks (Pizzignacco et al., 2010). Treatment is most effective with an early diagnosis of CF and a comprehensive treatment plan. Specialty clinics for CF are found in many communities; these generally focus on children or adults (A.D.A.M. Medical Encyclopedia, 2012).

Lung and sinus infections are typically treated and prevented using antibiotics at higher than normal dosages. Medications that are inhaled are used to open airways and DNase enzyme therapy is used to thin mucus, making it easier to cough up. Mucus is also thinned through aerobic exercise and other therapies such as a Percussion Vest, manual chest percussion, A-capella, or TheraPEP devices. If lung disease gets worse, oxygen therapy may be used. In some cases, lung transplant is required. Along with antibiotics, yearly influenza and pneumococcal polysaccharide vaccines are used to prevent lung problems (A.D.A.M. Medical Encyclopedia, 2012).

Diets high in protein and calories for older children and adults are prescribed to treat nutritional problems that result from the buildup of mucus in the pancreas. The mucus buildup affects the pancreas' ability to absorb proteins and fats, thus pancreatic enzymes are often taken to assist in absorption. Other supplements include vitamins A, D, E and K (A.D.A.M. Medical Encyclopedia, 2012). People with CF are encouraged to drink plenty of fluids, especially during hot weather, during physical activity or during episodes of diarrhea. Exercising is an important component of treatment, especially

activities such as swimming, jogging and cycling which are low-contact sports (A.D.A.M. Medical Encyclopedia, 2012).

Those diagnosed with CF must avoid smoke, dust, dirt, fumes, household chemicals, fireplace smoke, and mold or mildew (A.D.A.M. Medical Encyclopedia, 2012). They also must clear mucus from airways one to four times a day. Percussion and postural draining are important for patients, families, and caregivers to understand in order to properly take care of someone with CF.

Prognosis

Children with CF are typically healthy and able to participate in activities normally and attend school. Today, many people with CF are finishing college and able to find employment. The average lifespan has dramatically increased in the last three decades, as treatment has improved to approximately 37 years. Lung disease worsens until the point where a person is disabled and, typically, complications are the cause of death in those with CF (A.D.A.M. Medical Encyclopedia, 2012).

Chronic respiratory infection is the most frequent complication of CF. Other complications include: bowel problems including gallstones, intestinal obstruction and rectal prolapse; coughing up blood; chronic respiratory failure; diabetes; infertility; liver disease or failure; pancreatitis; biliary cirrhosis; malnutrition; nasal polyps; sinusitis; osteoporosis; arthritis; recurrent pneumonia; pneumothorax, and cor pulmonale, or right-sided heart failure (A.D.A.M. Medical Encyclopedia, 2012).

Stigma

Defining Stigma

Lasalvia et al. (2012) define stigma as “a mark or sign of disgrace usually eliciting negative attitudes to its bearer” (p.55). It is further broken down into three main areas of difficulties: knowledge, attitudes, and behavior. Knowledge can lead to stigma through ignorance or misinformation. Attitudes typically affect stigma through prejudice. Last, behavior leads to stigma through discrimination, or excluding one from normal forms of social participation (Lasalvia et al., 2012). When one believes that most people will devalue and discriminate against those who use a specific health service or who have a disease or illness, it is known as perceived stigma. Perceived stigma is a powerful obstacle to seeking care for those who may need it (Sirey et al., 2001).

Chronic Disease and Stigma

Stigma is often associated with many different chronic health conditions and leads to suffering and distress of those who are stigmatized (Jacoby et al., 2004). Stigma experienced by those with a chronic health condition can lead to psychological stress, depression, fear, participation restrictions and increased risk of disability and advanced disease. Other negative effects include delay in diagnosis and treatment, more severe morbidity, and poorer treatment prognosis (Van Brakel, 2006).

Courtesy Stigma

Courtesy stigma is when stigma affects people who are closely associated with those who are stigmatized, such as caregivers, family members, friends, or professionals who work with the stigmatized. For family members, it can result in teasing, abuse, and

blame placing, or holding the family responsible for a member's disability or illness. This can lead to family members' developing negative self-evaluations and negative emotions, further leading to withdraw or concealment (Ali, Hassiotis, Strydom, & King, 2012). Parents of children with genetic conditions are vulnerable to courtesy stigma, as they harbor feelings of guilt and shame related to having a child with a genetic condition (Chapple, May, & Champion, 1995; S. Kessler, Kessler, & Ward, 1984). Courtesy stigmatization can lead a person to want to dissociate from the stigmatized person, however in the caregiver relationship, this is not typically practical, socially permissible, or desired; thus, coping strategies must be developed (Turner, Biesecker, Leib, Biesecker, & Peters, 2007). With an increase in depression levels, coping can become increasingly difficult for the person who receives courtesy stigma.

Turner et. al (2007) looked at courtesy stigma in parents of children with Proteus syndrome (PS), a genetic condition that is progressively disfiguring. The researchers found that 97% (n=30) of parents reported at least one openly stigmatizing experience related to the child with PS. Additionally, some parents reported that they no longer had same relationships with family and friends. Fully, 23% (n=7) reported experiencing persistent worry that their child would be treated differently by others (Turner et al., 2007).

Stigma and CF

Stigma has been associated with CF, as it marks those who live with it thorough body deformity (barrel chest, clubbing of the feet), visible symptomology (cough, expectoration), the daily treatment rituals, and the barriers to social relationships these treatments may cause. For families of children with CF, comparing their lives to those of

the families of healthy children can lead to perceived stigmatization. Other impacts on families of those with CF include social isolation and distancing from social functions, like work (Pizzignacco et al., 2010).

Depression

Description

Depression ranks third among the leading contributors to global burden of disease, and first in middle and high-income countries. Depression can be easily diagnosed in primary care settings as well as in specialty services. While less than half of those with depression receive treatment, antidepressants and psychotherapy is effective in 60-80% of those with depression who seek treatment (Lasalvia et al., 2012).

Depression in Caregivers

Several studies have shown that caregivers are more likely to be depressed than non-caregivers (Baumgarten et al., 1992; Berg-Weger, McGartland Rubio, & Tebb, 2000; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Schulz, Tompkins, & Rau, 1988; Strawbridge, Wallhagen, Shema, & Kaplan, 1997). Rates of depression in caregivers have ranged from 38% to 60%, and female caregivers are more likely to be depressed than males (Baumgarten et al., 1992; Berg-Weger et al., 2000). It has also been found that younger age caregivers are at increased risk for depression (Schulz et al., 1988). Other risk factors include stress and personality of the caregiver, increased caregiver roles, decreased perceived self-mastery of caregiving, poor health of caregiver, history of depression in caregiver, and few financial resources (Baumgarten et al., 1992; Berg-Weger et al., 2000).

Depression has been studied as a mediator of caregiver well-being and strain. One study by Berg-Weger et al. (2000) found that depression explains 56% of the variance in activities of living and 64% of the variance in basic needs; these are the two components of caregiver well-being. This study identified depression as a mediator between stress and well-being. Researchers also found that perception of caregiving competence was positively related to well-being. Overall, they suggested that, as the caregiver's level of depression increases, he/she is less able to meet expectations for daily functioning. This can, then, affect ability of the caregiver to give adequate care (Berg-Weger et al., 2000).

Depression in Caregivers of Children with CF

CF is one of the most demanding chronic illnesses to manage in children. As the regimen for treatment and medication adherence is highly dependent on parent responsibility for administering and supervising CF treatment, increased role strain and symptoms of depression have been found among CF caregivers (Besier et al., 2011).

The prevalence of depression is higher in mothers of young children than in the general population, and mothers caring for children with a chronic illness are particularly at risk. Thus, there has been a need to study depression in the caregivers of children with CF (Driscoll et al., 2010). Caregivers of CF patients have been examined since the 1960s, and most studies indicate they experience lives that are high in distress and increased risk for depressive symptoms (Besier et al., 2011).

Quittner et al. (1992) first studied the relationship among specific chronic illness stressors and depression in caregivers of infants and toddlers recently diagnosed with CF. The study consisted of both mothers (n=36) and fathers (n=28) of children recently

diagnosed with CF. The Symptom Checklist-90 Revised (SCL-90-R) and the Center for Epidemiologic Studies Depression Scale (CES-D) were used to measure depression in the sample. Using the SCL-90-R, the authors found elevated levels of depression in parents of children recently diagnosed with CF; scores were two standard deviations above the SCL-90-R norms. The CES-D also showed elevated levels of depression with 64% of mothers and 43% of fathers scoring above 16, indicating possible depression.

Additionally, the authors found that mothers reported higher levels of depression than fathers and that role strain related to CF was associated with these higher levels of depression in mothers. Recommendations were made to further study homogenous populations by illness and child developmental age through conceptual frameworks. This will assist in understanding family functioning related to childhood chronic illness (A. L. Quittner, DiGirolamo, Michel, & Eigen, 1992).

Risk for parental depression after diagnosis of CF in a child was studied by Glasscoe et al. (2007). The authors used the Beck Depression Inventory (BDI-II) to compare depression levels among couples with a child diagnosed with CF (n=45) and matched control couples (n=45). A score of ≥ 13 , indicating dysphoria, or mild depression, was more prevalent among the CF couples when compared to the non-CF couples, however not statistically significant. When stratified by age of child, parents of children ≤ 9 months of age were found to have higher depression scores than those of children ≥ 10 months of age. This indicates that parents of children diagnosed earlier in life may be a greater risk for depression (Glasscoe, Lancaster, Smyth, & Hill, 2007).

Depression-anxiety parameters and sleep quality were studied in mothers of children with chronic respiratory disease by Yilmaz et al. (2008). Mothers of children

with asthma (n=62), mothers of children with CF (n=21), and mothers of healthy children (n=35) were included in the study. Depression was assessed using the hospital anxiety depression scale (HADS) and sleep was assessed using the Pittsburgh Sleep Quality Index (PSQI). The authors found that HADS and PSQI scores were higher in the CF and asthma groups when compared to the healthy control group, however were not statistically significant. It was also found that sleep scores and anxiety and depression scores were significantly correlated in the CF and asthma groups (Yilmaz et al., 2008).

Several other studies have found consistent findings. Smith et al. (2010) found that youth with CF and their parents report elevated depressive symptoms. Depression levels in parents were assessed using the CES-D, with 35% of mothers and 23% of fathers scoring above 16 (Smith, Modi, Quittner, & Wood, 2010) Driscoll et al. (2010) found that many caregivers of children with CF experience depressive symptoms. The study included both caregivers of children with type 1 diabetes (T1D) (n=108) and caregivers of children with CF (n=87) who participated in the HANDling Diabetes/CF multisite, randomized clinical trial. This study was designed to test the effectiveness of an adherence intervention delivered with routine clinic care to patients diagnosed with either CF or T1D. A third of caregivers of children with T1D and 32.3% of caregivers of children with CF reported depression symptom scores above 16 using the CES-D. The authors also found that the best predictors of depressive symptoms for primary caregivers of children with CF were higher family stress and lack of employment outside of the home. Recommendations were made for screenings of caregiver for depressive symptom to become a part of routine clinic visits to provide the opportunity for intervention (Driscoll et al., 2010)

Perceived Stigma and Depression

Stigma and depression have often been linked in the literature. The concept of stigma is often credited to the labeling theory, which proposes that stereotypical attitudes about those diagnosed with a mental illness, such as being incompetent and dangerous, can become personally relevant to the person who has the diagnosis. This leads to the person expecting to be devalued and discriminated against, almost a self-fulfilling prophecy, lowering their self-esteem and demoralizing them. Another negative outcome related to stigma is using coping strategies such as secrecy, disclosure, or social withdrawal, to allow the individual to avoid rejection. This may result in unemployment and lowered income. Additionally, stress may then increase, due to the lowered self-esteem and sparse social networks (Markowitz, 1998). Perceived stigma in mental illness arises when one believes that most people will devalue and discriminate against him or her if he or she uses mental health services and/or has a mental illness diagnosis (Sirey et al., 2001).

Markowitz et al. (1998) examined the relationships between stigma, psychological well-being, and life satisfaction among persons with mental illness. They used cross-sectional and lagged regression models with data from 610 individuals in self-help groups and outpatient treatment. Results found that 72% of respondents felt that a person with a mental illness will be devalued and discriminated against. Half the respondents indicated having experienced discrimination in the past six months. Additionally, the study found that stigma was related to depressive and anxiety symptoms (Markowitz, 1998).

Sirey et al. (2001) found that patients' perceptions of stigma at the start of treatment influence their subsequent treatment behaviors. They also found that younger patients reported perceiving more stigma than other patients, and that stigma predicted treatment discontinuation among older patients (Sirey et al., 2001). This is important to understand as cystic fibrosis is a disease of younger persons and requires much adherence to treatment in order to have a positive prognosis and delay the onset of worsening disease.

Caregiver Strain

Caregiver strain has been frequently studied as one outcome of caregiving of a family member with a chronic illness. It has been found that 15% of the caregiving population has had serious physical and mental health effects due to caregiving. Mental health problems have been important to practitioners as they can assess and plan interventions to respond to these problems. Additionally, it has been suggested that the perceptions of caregiving-related problems by caregivers may have more influence on mental health than the actual problem that is occurring (Berg-Weger et al., 2000).

Caregiver Strain and CF

As for other caregivers, role strain has been studied for caregivers of children with CF. Quittner et al. (1998) compared role strain in parents caring for children with and without CF, looking specifically at marital satisfaction and psychological distress. The researchers collected data on sixty-six couples with one or more children, half caring for children with CF. They found that there were higher levels of conflict over parenting, a greater number of child-care tasks, a great discrepancy between real and ideal division of role, and fewer positive daily interactions with couples of children with CF compared to

those couples of children without CF ($F=2.94$, $p<0.5$). It was also found that couples in the CF group spent more time in child-care and medical tasks than couples in the comparison group ($F=13.61$, $p<.001$) (Alexandra L. Quittner et al., 1998). These results show that couples caring for a child with CF have greater role strain than couples caring for children without illness.

Conclusion

As stigmatization of CF and depression have both been shown through research to be of concern for caregivers of children with CF, the association between stigma and depression in these caregivers warrants research. When applying the constructs of TRA, and looking into previous research into CF, caregiver strain, depression, and stigma, there is a need to understand how these factors relate in order to direct future research about causal factors, interventions, and best prevention methods.

Chapter III. Method

Participants

Target Population

The target population for this study was caregivers of patients with CF visiting the Emory-Children's Center Pulmonary, Apnea, Cystic Fibrosis, and Sleep Clinic, located in Atlanta, Georgia. The sample consisted of 35 caregivers who provided informed consent and completed the self-report depression and stigma questionnaire (Appendix A).

Recruitment

Researchers used a convenience sample of those who were visiting the clinic during the data collection period; selection was not random. Participants were identified and recruited from the waiting room and from patient rooms at the Emory-Children's Center Pulmonary, Apnea, Cystic Fibrosis, and Sleep Clinic. Subjects included the caregivers of children diagnosed with CF who were being seen during the data collection period.

Procedures

Data were collected through an anonymous, written survey distributed in-person, which occurred over a three-month period from December 2012 – February 2013. The principal investigator and a research assistant distributed questionnaires at Emory-Children's Center Pulmonary, Apnea, Cystic Fibrosis and Sleep Clinic, and requested that participants return their anonymous questionnaires to a secure box located in the clinic. Total respondent burden was approximately twenty minutes.

Measures

Sample

The sample provided information on the seven variables of age, number of children with CF, age of children with CF, relation to children with CF, sex, marital status, and child(ren)'s length of CF diagnosis. The continuous variable, age, was assessed by asking "How old are you?" Number of children with CF and age of children with CF were assessed by requesting the respondent to, "Please provide the age(s) of child(ren) with cystic fibrosis for whom you are the caregiver." Length of diagnosis of children with CF was indicated by asking, "How long has your child(ren) had a diagnosis of cystic fibrosis?" Both questions were answered with caregivers providing years and months for up to five (5) children with CF for whom they are the caregiver. Relation of caregiver to children was assessed by asking "What is your relation to the child(ren) for whom you are the caregiver?" and participants answered with one of the following: mother, father, grandmother, grandfather, uncle, aunt, sister, brother, other legal guardian (male), other legal guardian (female), or other (please specify). The categorical question of sex was answered with male, female, or transgender. Additionally, marital status was answered with single (never married), married, separated, divorced, or widowed.

Study Variables

To measure the presence and severity of depressive symptoms, the Center for Epidemiologic Studies Depression Scale (CES-D) was used. The CES-D is a 20-item, self-report tool, and uses a 4-point Likert-type scale to rate the extent to which the respondent experienced each state over the past week. Answers range from "rarely or

none of the time (less than 1 day)” to “Most or “all of the time (5-7 days),” and responses were assigned a score of 0-3. Sample statements include “I did not feel like eating, my appetite was poor,” and “I felt I was just as good as other people.” The total depression score was computed by summing the responses to all 20 items. Total scores range from 0-60 and standard cutoffs are ≥ 16 for possible depression and ≥ 23 for probable depression. Internal consistency reliability for the overall CES-D scale is good ($\alpha = 0.88$) (Thombs et al., 2008). Four questions which were negatively phrased were re-coded, in order to appropriately compute a total depression score.

To measure perception of stigma, the Parent Stigma Scale by Austin et al. (2004) was used. It is a five-question, Likert-type scale that was developed for parents of children with epilepsy and adapted for parents of children with cystic fibrosis. It ranges from 1 (strongly disagree) to 5 (strongly agree). The five items are summed and divided by the number of items, with a higher score reflecting a greater perception of stigma. Sample questions include “People who know that _____ has cystic fibrosis treat him/her differently,” and “Because of the cystic fibrosis, _____ will have problems in finding a husband or wife.” It is been shown to have good internal consistency reliability ($\alpha=0.79$) and validity (Austin, MacLeod, Dunn, Shen, & Perkins, 2004).

Risks of Participation

The only foreseeable risks or discomforts for participants was possible distress associated with considering that his/her child is stigmatized, or talking about his/her depression. In order to reduce this risk, if a participant felt uncomfortable with a question, he or she could skip that question or withdraw from the study altogether. If the participant decided to quit at any time before he or she had finished the questionnaire, answers were

destroyed. To minimize risks and ensure the safety of subjects, contact information for mental health and counseling was made available in the informed consent and at the end of the survey.

Plans for data management and monitoring

All data were collected anonymously and kept completely confidential. Data were only seen by the investigators, and kept in a secure file and desktop at Rollins School of Public Health to which only the principal investigator and student researcher had access.

Confidentiality

This survey was completely confidential. Researchers did not know the participant's name when he or she responded to the survey. Data were assigned a participant number, and only the researchers saw the individual survey responses.

Informed Consent

This study did not collect signed consent because it would be the only identifying information collected from the respondent. To ensure that consent was obtained, the first page of the survey instrument contained the elements of consent (see Appendix B) and explained that completion of the survey instrument constituted the participant's provision of informed consent to participate in the survey. Capacity to give informed consent was assessed by the ability to read and complete the survey instrument. The following information was communicated to the participant: purpose of the study, what would be done, benefits of the study, risks or discomforts, confidentiality, the right to quit at any time, how the findings would be used, and investigator contact information.

Data Collection Instrument

The survey instrument is attached as Appendix A. It is comprised of investigator-initiated items and reliable screening tools. The investigator-initiated part of the survey was developed to determine demographics and evaluate aspects of the relationship to the child with cystic fibrosis and his or her disease. These items included the following: age and sex of participant, age and sex of child(ren) with CF, caregiver relation to child(ren), marital status, and length of child(ren)'s diagnosis of CF. The CES-D, a 20-item, self-report tool, was used to evaluate depression. Answers were on a 4-point, Likert-type scale to rate the extent to which the respondent experienced each state over the past week. Perception of stigma was measured using the Parent Stigma Scale, which is a five-question Likert-type scale. Answers range from 1 (strongly disagree) to 5 (strongly agree).

Analysis Procedures

Data was analyzed using IBM SPSS Statistics 20. To assess reliability of the CES-D and the Parent Stigma Scale, Cronbach's alpha was calculated. This test measures internal consistency reliability in the current study sample with a result of ≥ 0.70 having a good reliability (Thombs et al., 2008). Data analysis of the research questions was performed using two different tests. For the analysis of the first question, which asks if there is a correlation between perceived stigma and depressive symptoms, the researcher used the Pearson product-moment coefficient of correlation. It is the most commonly used measure of correlation (Portney & Watkin, 2009).

For the analysis of the second question, asking if the correlation persists when other variables are controlled, the researcher used a multiple linear regression. The

dependent variable was depressive symptoms and the independent variables were perceived stigma, gender of the caregiver, age of the caregiver, relationship to the child, caregiver's marital status, number of children, child's age, and duration of the child's diagnosis.

Missing data were made into their own category, to test the null hypothesis that non-respondents were no different from respondents. The two groups were compared to see if there were any statistical differences between groups. Statistical differences were taken into account when looking at results. Missing data were also handled in analysis by using listwise deletion.

Chapter IV. Results

Descriptive Statistics

The analysis consisted of 35 of the 36 surveys obtained (Table 1). One survey was eliminated based on inconsistency in answers. When asked about age, all 35 participants answered, with the average age of 39.31 (sd=9.628) and median age of 40.00. The average age of a caregiver's first child was 9.6 (n=35; sd=5.9) and the average age of a caregiver's second child was 14.3 (n=4; sd=2.1). The average length of diagnosis of a caregiver's first child was 7.4 (n=35; sd=5.8) and the average of length of diagnosis for the second child was 13.9 (n=4; sd=1.8). Mothers made up 71% of caregivers (n=25), while 17% (n=6) were fathers, 8.6% (n=3) were grandmothers and 2.9% (n=1) was a stepmother. Females made up 80% (n=28) of the respondents, while males constituted 20% (n=7). Reported marital status showed that 71% (n=25) were married, 22.9% (n=8) were divorced, and 5.7% (n=2) were single. For distribution tables see Appendix C.

For this sample of caregivers of children with CF, the Cronbach's coefficient alpha for the CES-D was 0.945. The Center for Epidemiologic Studies Depression Scale (CES-D) found an average depression score of 10.8 (sd=11.3) out of 60 possible points for 33 participants. Two participant's scores were not totaled due to incomplete scale responses. Scores ranged from 0 to 41 with 14.3% (n=5) having scores of ≥ 16 , indicating possible depression, and 14.3% (n=5) having scores of ≥ 23 , indicating probable depression.

For this caregiver sample, the Cronbach's coefficient alpha for the Parent Stigma Scale was 0.688. The average stigma score on the Parent Stigma Scale was 2.4 (sd=0.7) out of 5 possible points for 34 participants. This is in the midrange between no perceived

stigma (score = 1) and high perceived stigma (score = 5). Scores ranged from 1 to 3.8.

One score was not calculated due to incomplete scale response.

Table 1. Descriptive Statistics

	N	Mean (sd)	Minimum	Maximum
Age of caregiver in years	35	39.31 (9.63)	22	66
Age of child 1 with CF in years	35	9.60 (5.89)	0.25	17.92
Child 1 diagnosis length in years	35	7.36 (5.84)	0.00	17.00
Age of child 2 with CF in years	4	14.33 (2.14)	12.50	17.33
Child 2 diagnosis length in years	4	13.88 (1.81)	12.42	16.25
Stigma total score	34	2.44 (0.69)	1.00	3.80
Depression total score	33	10.76 (11.34)	0.00	41.00
			N (%)	
Depression Categories			<i>No Depression (<16)</i>	23(65.7)
			<i>Possible Depression (≥16)</i>	5(14.3)
			<i>Probable Depression(≥23)</i>	5(14.3)
Caregivers Relation to child			<i>Father</i>	6 (17.1)
			<i>Grandmother</i>	3 (8.6)
			<i>Mother</i>	25 (71.4)
			<i>Stepmother</i>	1 (2.9)
Caregiver's sex			<i>Female</i>	28 (80.0)
			<i>Male</i>	7 (20)
Caregiver's marital status			<i>Single</i>	2 (5.7)
			<i>Married</i>	25 (71.4)
			<i>Divorced</i>	8 (22.9)

Research Question 1

Q1. Are levels of perceived stigma associated with level of depressive symptoms among caregivers of children with cystic fibrosis?

A Pearson correlation test was performed to examine the association between depressive symptom levels and perceived stigma of child with cystic fibrosis in caregivers of children with cystic fibrosis (Table 2). There was a statistically significant association ($r=0.436$; $p=0.013$, $n = 32$), suggesting that with increased perceived stigma, depressive symptoms also increase.

Research Question 2

Q2. Are levels of perceived stigma associated with levels of depressive symptoms among caregivers of children with cystic fibrosis when sex of the caregiver, age of the caregiver, relationship to the child, caregiver's marital status, number of children, child's age, and duration of the child's diagnosis are controlled?

Bivariate analyses (Table 2) suggest that perceived stigma scores ($p=0.013$) and sex of the caregiver ($p<0.001$) were independently, significantly associated with depression scores. There was no significant relationship between depression scores and age of the caregiver ($p=0.180$), relation to child ($p=0.853$), caregiver's marital status ($p=0.668$), number of children ($p=0.580$), child's age ($p=0.959$) or duration of child's diagnosis ($p=0.669$). Therefore, only perceived stigma scores and sex of the caregiver variables were included in a subsequent linear regression model using the Enter method. No collinearity existed between stigma scores and sex of the caregiver when coefficient correlations were run ($r= -0.17$) (Table 3).

Table 2. Correlations of Depression Scores and Stigma Scores with Model Variables

		Depression Score	Stigma Score
Stigma Score	<i>Pearson Correlation</i>	0.436*	1
	<i>Significance</i>	0.013	
Age of Caregiver	<i>Pearson Correlation</i>	-0.239	0.108
	<i>Significance</i>	0.180	0.544
Sex of Caregiver	<i>Pearson Correlation</i>	0.595*	0.183
	<i>Significance</i>	0.000	0.299
Number of Children	<i>Pearson Correlation</i>	-0.100	-0.355*
	<i>Significance</i>	0.580	0.039
Age of Child	<i>Pearson Correlation</i>	0.009	0.100
	<i>Significance</i>	0.959	0.572
Length of Diagnosis	<i>Pearson Correlation</i>	-0.078	0.141
	<i>Significance</i>	0.668	0.427
Marital Status	<i>ANOVA</i>	p=0.051	p=0.676
Relation to Child	<i>ANOVA</i>	p=0.061	p=0.686

*Correlation is significant at the 0.05 level

Table 3. Coefficient Correlations

		Sex	Stigma Score
Correlation	<i>Sex</i>	1.000	-0.170
	<i>Stigma Score</i>	-0.170	1.000
Covariance	<i>Sex</i>	14.070	-1.471
	<i>Stigma Score</i>	-1.471	5.296

Dependent Variable: Depression Score

The multiple linear regression found that the overall model including sex and stigma was significant ($F_{2,29}=12.617$; $p<0.000$). The total regression model accounted for 46.5% of the variance in depression scores. Results of the regression model suggest that both perceived stigma scores and sex of the caregiver were significantly associated with depression scores (Table 4). Perceived stigma uniquely explained 11.6% of the variance in depression, while sex uniquely explained 27.6% of the variance, and 7.3% of explained variance was shared by the two variables. For each unit increase in stigma scores, depression increased on average by 5.767 points, when controlling for sex ($B=5.767$; 95%CI= 1.061, 10.474; $p=.018$). On average, males had a depression score that was 14.490 points higher than that of females when controlling for perceived stigma scores ($B=14.490$; 95%CI=6.818, 22.162; $p=.001$).

Table 4. Multiple Linear Regression Coefficients

	Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.	95% Confidence Interval for B		Correlations		
	B	Standard Error				Lower Bound	Upper Bound	Zero-order	Partial	Partial
Constant	-6.408	5.805		1.104	.279	18.281	5.465			
Stigma Score	5.767	2.301	.345	2.506	.018	1.061	10.474	.436	.422	.340
Sex	14.490	3.751	.532	3.863	.001	6.818	22.162	.591	.583	.525

a. Dependent Variable: Depression Score

Chapter V. Discussion

Findings

The purpose of this research study was to investigate the relationship between depression and stigma in caregivers of children with CF. Prior research has found that stigmatization of CF and depression have both been seen as a reason for concern among CF caregivers. The first research question was to determine if, in fact, there is an association between perceived stigma the level of depressive symptoms among caregivers of children with cystic fibrosis. The second research question was aimed at determining if other factors, such as gender of the caregiver, age of the caregiver, relationship to the child, caregiver's marital status, number of children, child's age, and duration of the child's diagnosis, changed the association of perceived stigma associated with levels of depressive symptoms among caregivers of children with cystic fibrosis. The answers from the questions above were found to be statistically significant and important for the cystic fibrosis and caregiver community.

Average depression scores were relatively low among these caregivers of children with CF, although some scores suggested possible or probable depression. This pattern is similar to other studies using the CES-D for measure depression in caregivers (Driscoll et al., 2010; A. L. Quittner et al., 1992; Smith et al., 2010). Similarly, a meta-analysis showed that CES-D scores ranged from 5.6 – 28.9 across six studies for caregivers, higher than rates in non-caregiving groups (Schulz, Visintainer, & Williamson, 1990). On average, caregivers in this study perceived low stigma related to their child with CF, although some did experience higher levels.

The analyses found that, as perceived stigma scores increased, so did depression scores. Thus, in answering the first research question, perceived stigma was and

significantly associated with depression symptoms. The age of the caregiver, relationship to the child, caregiver's marital status, number of children, the child's age, and the duration of the child's diagnosis were not significantly associated with depressive symptoms, but sex was. In answering the second research question, perceived stigma scores were associated with depressive symptoms when sex was controlled. However, males were found to have higher depression scores when perceived stigma scores were controlled.

It has been found in the literature that when compared to male caregivers, female caregivers spend more time as care providers, perform more caregiving tasks, experience caregiver burden and depression at higher levels. Additionally, female caregivers have lower levels of physical health and subjective well-being (Pinquart & Sorensen, 2006). The higher depression scores found in male caregivers may have been related to the fact that the survey was distributed at the CF clinic during his child's appointment. If the male caregiver spends less time as a care provider and performs less caregiving tasks, this may have negatively influenced his emotions during the visit.

Conclusions

This study found a significant relationship between perceived stigma and depression in caregivers of children diagnosed with CF. Based upon previous literature, it is possible that perceived stigma and depression may operate together to undermine the caregiving provided to children with CF. Furthermore, understanding that perceived stigma and depression are linked may provide new opportunities for intervention upon the depression of CF caregivers.

Strengths and Limitations

Two major strengths in this study are its theoretical basis and novel research topic. Theory driven research provides a strong basis for research development. The Theory of Reasoned Action guided development this study, providing direction and justification for research. Additionally, this was the first study of this issue. Understanding the link between perceived stigma and depression may influence and direct future research on this topic.

Methodology

The methods of this study had a few limitations. A major limitation of this study is that it is cross-sectional and only shows what was happening with each participant at that point in time. Also with a cross-sectional study one cannot predict what came first: the outcome or the exposure. With this study it cannot be assumed that perceived stigma leads to depressive symptoms or that depressive symptoms lead to perceived stigma. While depression was treated as the dependent variable in this study, suggesting that perceived stigma influences depressive symptoms, it is just as possible that depressive symptoms may influence the perception of stigma. Future research should use a longitudinal study to look at the change in depressive symptom levels and perceived stigma from diagnosis through the lifespan of the study.

In addition, the questionnaires were self-report with no directly observed behavior. Thus, answers could be given based on perceived norms. Participants may also have answered based on social desirability or felt embarrassed to report private details. To attempt to decrease this concern, the surveys were collected without identifying information. Responses may also have been affected by whether a participant

felt good or bad at the time of completing the questionnaire. Bias can also result if those who did respond answer the survey or certain questions differently than those who did not respond might have.

Sample Size and Recruitment

While the sample size was smaller than expected ($n=35$) and may be considered a limitation, the Central Limit Theorem states that assumptions of normality usually require a sample size of 30 or greater (Wedler, 2010). When controlling for sex, a sample size of 30 or greater was not achieved, but the effect was sufficiently large to achieve statistical significance with the smaller sample.

Another limitation was that the study only examined those caregivers whose children were receiving treatment at Emory-Children's Center Pulmonary, Apnea, Cystic Fibrosis, and Sleep Clinic. Thus, information found may not be generalizable to all caregivers of persons with CF as this clinic may serve a particular demographic.

Because confidentiality was a priority, surveys were completely anonymous, which did not allow the research team to keep track of who and how many had already taken the survey, been approached to take the survey, refused to take the survey, and had not returned the survey to the locked-box. If identifiers had been collected, further measures may have been possible for recruiting participants into the study. However, collecting anonymous surveys was appropriate in this population due to the sensitive nature of the questions asked. Additionally, as the study was not directly sponsored by the clinic, motivation to participate may have also been lower. Other limitations included the fact that Institutional Review Board (IRB) approval was obtained late in the research process, thus administration of the surveys was given in a limited time frame of 2.5

months. Additionally, research staff was limited to one individual. Lastly, no incentive was offered to research participants, which may have decreased motivation to complete surveys.

Instrument Design

A major strength of the instrument design was its use of reliable and validated interments. This ensures that the study questions accurately measure what is being asked and that answers are answered consistently across time points and settings. The instrument did have some flaws as pilot testing was not performed on the survey instrument and procedures. First, sex of the child with cystic fibrosis was not collected by the survey. It may have also been important to capture whether parents had other children, as well. For those that had more than one child with cystic fibrosis, it was difficult to understand whether the parent felt the same perceived stigma for one or both of the children when answering the questions.

Additionally, the length of the survey may have created participant burden, as there is often much going on during an office visit, limiting the time available to answer questions. A pilot test survey would have been the best solution to these issues. However, due to the limited time frame there was not an opportunity for piloting. A qualitative component of the survey, such as an open-ended question or focus-groups, may have provided additional information that the scales could not capture.

Implications and Recommendations for Research and Practice

Recommendation for Future Research

Additional research on the topics of perceived stigma and depression in caregivers should be performed in a larger population, in order to have a more accurate understanding of this issue. Also, having a comparison group of caregivers of children with other chronic illnesses can help determine if this association exists exclusively in the CF caregiver population. Along with using standardized scales on depression and stigma, qualitative research methods would provide important and insightful information that participants may not reveal on a quantitative instrument.

The wide range and standard deviation of depression symptom scores shows that depressive symptoms can be a problem in this population. It would be important to focus future research on those who meet criteria for depression within this population in order to further understand if this burden is more prevalent in caregivers of children with cystic fibrosis, and how that relates to stigma.

Implications for Public Health

As depressive symptoms are present in caregivers of children with CF, more attention and care should be directed towards this population. Caregivers should be regularly screened for depression symptoms as well as given resources for management and treatment of any symptoms present. Family-centered care is a concept that includes both patients and their families in the plan care by health professionals. The mental health management of family members is an important component to be included in this care model. Similarly, providers and other healthcare professionals can assess perceived stigma in caregivers of children diagnosed with CF to begin a conversation around

stigma. Those who do feel stigmatized may need to be connected to additional recourse to help combat stigma and/or cope with their own feelings. Educational recourse can also be provided for family and friends of caregivers and within the community to decrease stigma of genetic illnesses. Since stigma and depressive symptoms are shown through this study to be associated, when stigma or depressive symptoms are shown in a caregiver, it is important to assess whether the other is present in that individual.

Additionally, although males may appear as caregivers less often than females as seen in this study, special attention should be paid to this population. Males were found to have higher levels of depression when controlling for stigma according to analysis. Future research is warranted to study if this is a true trend in caregivers.

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Appendix

Appendix A. Data Collection Instrument

Part I. Demographics

1. How old are you? ____

2. Please provide the age(s) of child(ren) with cystic fibrosis for whom you are the caregiver?
 - Child 1: ____ years ____ months
 - Child 2: ____ years ____ months
 - Child 3: ____ years ____ months
 - Child 4: ____ years ____ months
 - Child 5: ____ years ____ months

3. What is your relation to the children for whom you are the caregiver? (check one box):
 - Mother
 - Father
 - Grandmother
 - Grandfather
 - Uncle
 - Aunt
 - Sister
 - Brother
 - Other Legal Guardian (male)
 - Other Legal Guardian (female)
 - Other (please specify): _____

4. Sex:
 - Male
 - Female
 - Transgender

5. Marital Status:
 - Single (never married)
 - Married
 - Separated
 - Divorced
 - Widowed

6. How long has your child(ren) had a diagnosis of cystic fibrosis?
 - Child 1: ____ years ____ months
 - Child 2: ____ years ____ months
 - Child 3: ____ years ____ months
 - Child 4: ____ years ____ months
 - Child 5: ____ years ____ months

Part II. Stigma

Please answer each of the following for the child(ren) with cystic fibrosis for whom you care by checking the box.

1. People who know that ___ has cystic fibrosis treat him/her differently.

1 – strongly disagree

2 – disagree

3 – neither

4 – agree

5 – strongly agree

2. It really doesn't matter what I say to people about ___'s cystic fibrosis(?), they usually have their minds made up.

1 – strongly disagree

2 – disagree

3 – neither

4 – agree

5 – strongly agree

3. ___ always has to prove him/herself because of his/her diagnosis of cystic fibrosis.

1 – strongly disagree

2 – disagree

3 – neither

4 – agree

5 – strongly agree

4. Because of the cystic fibrosis, ___ will have problems in finding a husband or wife.

1 – strongly disagree

2 – disagree

3 – neither

4 – agree

5 – strongly agree

5. In many people's minds, cystic fibrosis attaches a stigma or label to ___.

1 – strongly disagree

2 – disagree

3 – neither

4 – agree

5 – strongly agree

Part III. Depression

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week by checking a box.

	During the Past Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part III. Depression, Continued

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week by checking a box.

	During the Past Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I could not get “going.”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix B. Informed Consent

Emory University Rollins School of Public Health Consent to be a Research Subject

The purpose of this survey is to find out if depression and stigma are related in caregivers of children with cystic fibrosis. It is being done by Mary Danielle Kuykendall, Rollins School of Public Health graduate student, at Emory University in Atlanta, Georgia.

You are being asked to take a survey which takes about 20 minutes to complete. This survey includes questions that describe you (e.g. age, sex), questions about your child or children with cystic fibrosis, questions about depression and questions about stigma.

The only possible risks or discomforts of taking part are if you are uneasy thinking about the stigma of cystic fibrosis or uneasy answering questions about symptoms of depression. If you feel uneasy about a question, you can skip that question or withdraw from the study altogether. If you decide to quit at any time before you have finished the survey, your answers will not be recorded.

This study is not designed to benefit you directly. Expected benefits of this research include adding to the limited knowledge about how stigma and depression are related in caregivers of children with cystic fibrosis. These results may be used to help others in the future.

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. Emory will keep any research records we create private to the extent we are required to do so by law. This survey is completely confidential. Your name will not be on your survey. The data will be given a study number and only the study staff will see your survey answers.

Your taking part in this study is voluntary. You may withdraw from the survey at any time. If you do not wish to complete the survey, your answers will be discarded.

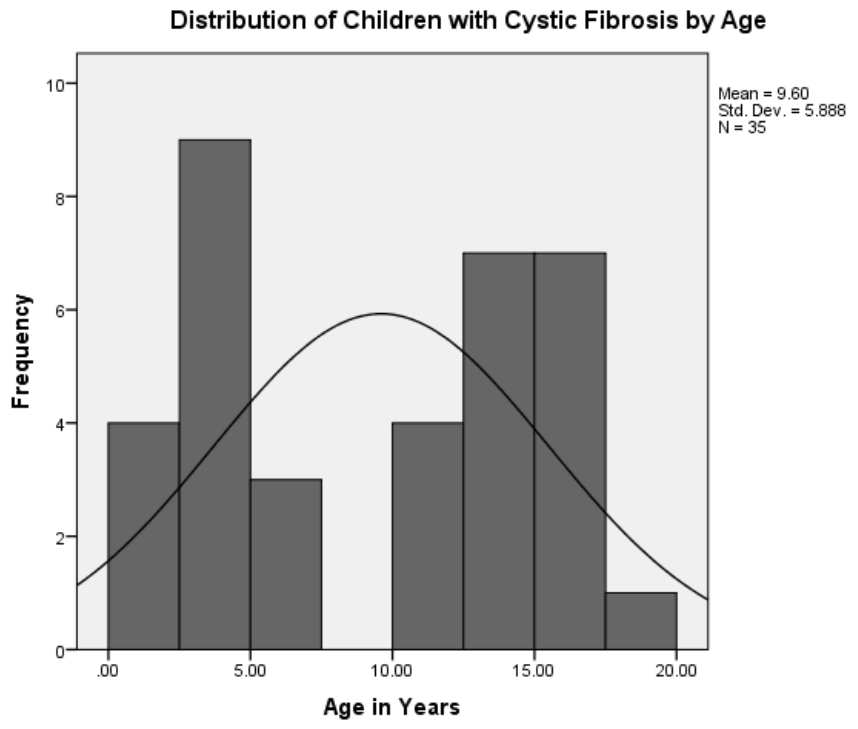
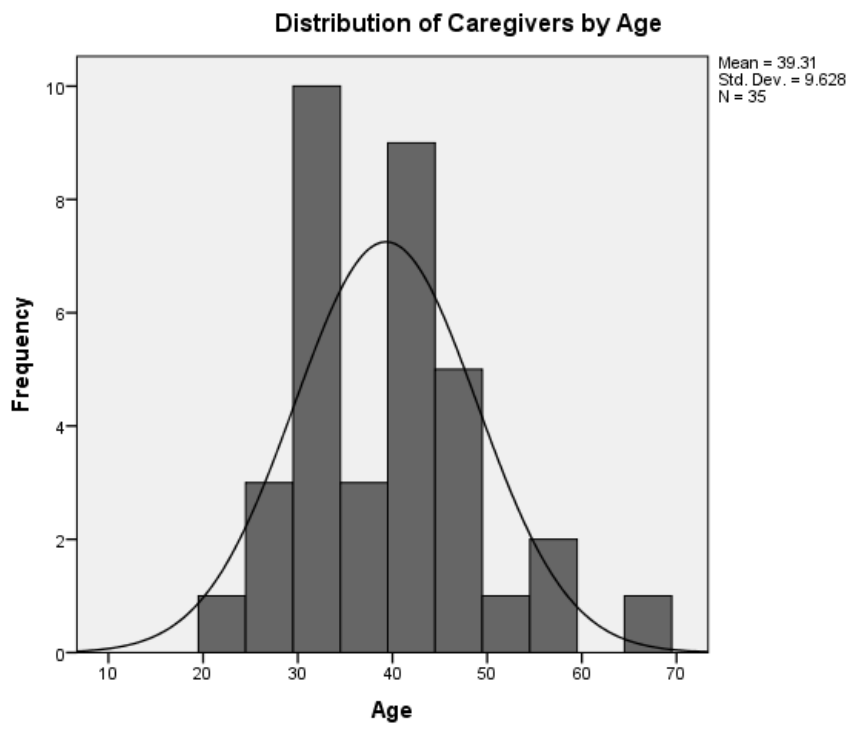
The findings will be used for scholarly purposes only. The results will be presented in educational settings and at professional conferences. The results may be published in a journal in the field of psychology or cystic fibrosis.

If you have any concerns or questions about this study, please contact Mary Kuykendall at mdkuyke@emory.edu. If you have any questions about your rights as a research participant, or concerns or complaints about the research, please contact the Emory University Institutional Review Board at 404-712-0720, 877-502-9797 or irb@emory.edu.

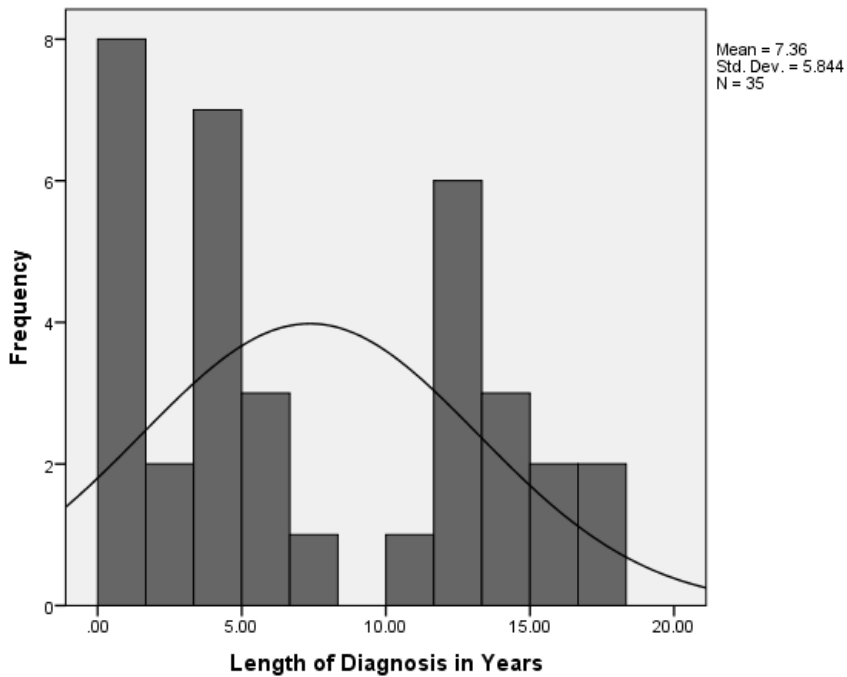
If you feel you are having symptoms of depression, you can obtain help from the Georgia Crisis and Access Line at 1-800-715-4225. If this is an immediate emergency, you may also call 911.

By filling out this survey, you are saying that you have read this consent form and agree to take part in this research and know that you are free to stop taking part at any time without penalty.

Appendix C. Distribution of Study Variables



Distribution of Diagnosis of Cystic Fibrosis Length by Age



Distribution of Depression Scores

