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The Relationship Between Hospitalizations and Anxiety and Depression Symptoms in Patients with Cystic Fibrosis

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ABSTRACT

In 2015, the Cystic Fibrosis (CF) Foundation collaborated with the European CF Society to develop new guidelines to screen for depression and anxiety in people with CF. The guidelines were based on a study that assessed over 6,000 patients and 4,000 caregivers among 45 centers in the United States and eight European countries. Research has proven that depression and anxiety have a negative impact on CF and overall health. 186 adolescents within the CF clinic at Children's Health Center voluntarily completed the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder (GAD-7). These screenings were completed between February 2016-March 2017 and the data was stored within an Excel Workbook. The existing data was then used for this study. Chart reviews were conducted on each of the patients to obtain the number of hospitalizations and length of stay as well as patient's gender. Statistical Package for the Social Sciences (SPSS) was used to analyze the correlation, if any, between depressive and anxious symptoms and hospitalizations or length of stay. A significant correlation was found between depression symptoms and gender ($p<0.05$). Females were significantly more likely to report depression symptoms compared to their male counterparts ($p<0.05$). Based on literature, adolescent males are less likely to report mental health symptoms. Further research needs to be completed to address the male population in regards to being open about addressing their mental health status. More research needs to be completed on mental health symptoms related to overall quality of life.

The Relationship Between Hospitalizations and Anxiety and Depression Symptoms in Patients with Cystic Fibrosis

A Thesis

Presented to

The Faculty of the Graduate School of Social Work

Abilene Christian University

In Partial Fulfillment

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Master of Science

Social Work

By

Ronni Taylor Barker

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This thesis, directed and approved by the candidate's committee, has been accepted by the Graduate Council of Abilene Christian University in partial fulfillment of the requirements for the degree

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This thesis is dedicated to the medical staff and patients that helped to develop this research. The dedication and passion of this team contributes to improving the level of care for patients with Cystic Fibrosis. We hope this will improve the patient’s overall quality of life based on the findings from this study

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This study continues to be researched at the Children's Health Cystic Fibrosis clinic in Dallas, Texas. Clinic staff involved in this study includes: Jamie Becker, PhD and Bonnie Jenkins, LCSW.

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CHAPTER I

INTRODUCTION

In 1938, Dorothy Anderson was the first person to recognize the symptoms of Cystic Fibrosis (CF) and helped create a way to test and diagnose the disease. Over time, it was determined to be a genetic disorder that requires time-consuming medical interventions. CF is characterized by lack of growth, pulmonary infections, and the absence of pancreatic enzyme secretion, which leads to nutritional failure (Cohen-Cymberknoh et al., 2006). It creates thick, sticky mucus within the lungs that adheres to airway surfaces (Cohen-Cymberknoh et al., 2006). The physical symptoms associated with CF may have implications for daily life, but the presence of depression and anxiety symptoms has also been found to impair daily functioning for adolescents – specifically in areas like socialization (Pinquart & Shen, 2010). During adolescence, biological, psychological, and sociological changes are occurring. Thought processes and cognitive abilities are maturing and growing. CF can interrupt these processes because it has the potential to delay puberty up to two years, which can result in stunted growth (Segal, 2008). Children during this stage are beginning to grasp the concept of a cause and effect relationship for any action made (Segal, 2008). They are still maturing to the point of being able to see the consequences for their actions, which is why management strategies for CF should be stressed (Segal, 2008).

Adolescents need accurate and consistent support while coping with a chronic illness because it may affect many areas of development. CF requires rigorous maintenance and time in order to have a higher quality of life (Cystic Fibrosis Foundation, n.d.). For instance, patients may have to do airway clearance techniques (ACTs) such as coughing, in order to loosen the mucus in their lungs (Cystic Fibrosis Foundation, n.d.). CF patients also take enzymes due to the nutritional failure and other medication such as nebulizer treatments, in order to fight infections (Cystic Fibrosis Foundation, n.d.). These treatments can require long periods of time in order to complete them. It is important to know how this affects family functioning, treatment adherence, and mental health of this population. Research has shown that people with CF are at a higher risk of developing symptoms of depression and anxiety (Quittner et al., 2014). The presence of depression and anxiety are two to three times higher among adolescents with CF than the general population (Quittner et al., 2014), and may interfere with the ability of adolescents and parents to maintain adherence. Given this bi-directional relationship between physical and mental health among patients with CF (Knudsen et al., 2016), it is hypothesized that patients who report having higher symptoms of depression and anxiety will also have a higher rate of hospitalization.

In 2015, the CF Foundation collaborated with the European CF Society to establish new guidelines to address the mental health aspect of the CF centers (CF Foundation, 2015). These guidelines include screening patients 12 to 17 years of age annually using the self-reported assessment which include the Patient Health Questionnaire (PHQ-9) and the Generalized Anxiety Disorder 7 (GAD-7). These told are designed to screen for depression or anxiety symptoms within the patient. Given past research and the mental health symptoms associated with CF, the purpose of this study is to determine how depression and anxiety symptoms correlate with hospitalizations among adolescent patients with CF.

CHAPTER II

LITERATURE REVIEW

Family Functioning

The way in which families are first told about a diagnosis is extremely important. When a parent is told that their child has a chronic life-threatening illness, it may result in a range of emotions. Caregivers may remember the day, location, how the information was given, and who told them. When a child is first diagnosed with CF, families may go through confusion, disbelief, anxiety, turmoil, and a loss of identity (Smith, Cheater, & Bekker, 2013). For some parents, the new information can potentially make it difficult to retain information and feelings of self=blame may begin (Smith et al., 2013).

Although it is difficult to receive a report of a new diagnosis, it is important for families to develop a routine as soon as treatments begin. This is to help families plan and organize their time so that they can maintain treatments and prioritize other necessities throughout their day (Grossoehme, 2014). By developing time management skills, the burden of treatment regimens may decrease (Grossoehme, 2014). It is acknowledged that developing a routine can be difficult especially for first time parents.

Once told of a new diagnosis, families may think immediately about the future and how it will look. This in turn may cause feelings of anxiety to arise. It is important to stress to caregivers how important it is to be open about how they are feeling so that they can develop healthy habits of open communication early on. For instance, as a child with a chronic illness begins to grow older, parents feel a sense of guilt for using respite services in order to take time for self-care, therefore they will not speak out about the need for this service. By allowing concerns and frustrations to build, separation of the caregivers can potentially increase (Douglas et al., 2015; Heywood, 2010 & McCoyd et al., n.d.). Therefore, emphasizing to parents the option for respite services is important to decrease high statistics of separation and improve or maintain their overall quality of life (Burton, 2008). If parents or caregivers are able to develop a habit of speaking about emotions, then resources can be available to help manage and cope with these emotions. This allows parents to tend to their own relationship so that the fear of separation diminishes (McCoyd et al., n.d.).

Findings show that a child with a chronic diagnosis can have the opposite effect on families. Some families state that their child's diagnosis brought them closer (McCoyd et al., n.d.). This could be caused by a common want to advocate and provide consistent help for their child. It appears that when both partners are actively involved in the child's care, the divorce rates are lowered (McCoyd et al., n.d.). Another positive result to equal involvement in care is the decreased likelihood of developing relationship strain between parent and child (Grossoehme, 2014). If there is a higher involvement emotionally between parent and child, this can result in higher reinforcement rates for treatments (Grossoehme, 2014). This in turn results in less child-parent conflict because the child can be actively involved in their care routines (Grossoehme, 2014). It is also known that becoming adapted to a child's illness is difficult and will take for families due to the consistent change that is occurring (Smith et al., 2013). Constant change can cause burn out in families both physically and mentally.

Chronic illnesses have shown to be a factor that promotes stress among families in general. Mothers felt stress from fear of being the main caretaker and fathers were stressed from the perception of maintaining the family provider role (Smoth et al., 2013). Approximately sixteen percent of mothers with children that have a chronic illness or disability are able to work compared to the sixty one percent of mothers that do not have a child with these concerns (Heywood, 2010). This ultimately results in lower family incomes, which limits a child's resources (Heywood, 2010). This can be a major stressor for parents and caregivers.

Parental stress has shown to be a risk factor among adolescents and their siblings (O'Haver et al., 2010). Parental stress and lack of social support has been linked to poor adaptation among the health siblings (O'Haver et al., 2010). This could be attributed to inconsistent family routines, lack of resources to help adjust to a new situation, or how the healthy siblings (O'Haver et al., 2010). This could be attributed to inconsistent family routines, lack of resources to help adjust to a new situation, or how the healthy sibling views the diagnosis and its (Everhart et al., 2014) impact on daily living. Siblings of adolescents with a chronic illness are at a greater risk to develop emotional and behavioral problems, which can be attributed to the parents prioritizing their time with the child that has the illness (Heywood, 2010). As a result, the siblings can have lower self-esteem, academic performance, and behavior and emotional delays (Heywood, 2010).

CF impacts treatment and personal care regimens, social and financial aspects, and relationships, which may disrupt how the family functions altogether. The treatment regimens required by CF take long periods of time and commitment. Many families have to wake up extremely early in order to help their child with breathing treatments. Furthermore, families tend to rely more on being task oriented rather than addressing the emotional or interactional pieces of their life due to the treatment regimens required by CF (Everhart, Fiese, Smyth, Borschuk, & Anbar, 2014). Therefore, identifying factors that impact a child and their family's quality of life is important for their overall health.

Financial concerns may be another source of stress for families coping with a chronic illness. Evidence shows that finances had a negative impact on parental relationships (O'Haver et al., 2010). Families with a child that has a disability have financial costs that are up to three times higher than families that are not raising a child with an illness or disability (O'Haver et al., 2010). With this high statistic it can be assumed that stress will potentially be associated with it. The stress and concern of finances negatively affect the adolescent's adaptation as well (O'Haver et al., 2010). It is important to note the evidence that suggests chronic illnesses do not impact a child's daily living or socialization (Denny et al., 2013 & Higham et al., 2013). This could be directly related to age, situation, or other outside factors.

Treatment Adherence

Family functioning significantly impacts treatment adherence because it is directly related to psychological functioning of the adolescent. Adhering to treatment regimens can be difficult at times due to the changes that are taking place during adolescence paired with a chronic illness. The research shows that the average rate of treatment adherence is at or below fifty percent, specifically in the CF population (Modi et al., 2006). Treatment adherence can only be maintained if the resources are available. The lack of resources needed for medications and equipment have also been shown to be a stressor among families. If a family cannot afford medications or equipment, treatment adherence significantly decreases.

Not adhering to treatments can have a range of negative effects. Some of these include: increased morbidity and mortality, lower quality of life, and increased healthcare costs. Adhering to treatments can be difficult when a family does not fully understand the treatment process, forgets the side effects of not adhering, or lacks the resources to be able to maintain treatment regimens (Hanghoj et al., 2014; Modi & Quittner, 2006). If a family lacks the resources to be able to maintain the treatment regimen, the overall quality of life of the patient will significantly decrease. Lower socioeconomic (SES) families may have worse outcomes in their child (Barr et al., 2011; Douglas et al., 2015; O'Connor et al., 2003 & Schechter et al., 2001).

Although there are many financial needs for families, the good news is that there are many programs and organizations that provide assistance by meeting specific criteria. For example, Medicaid waiver programs help with medications, medical devices, home modifications, or specific therapies. Financial assistance programs such as Supplemental Security Income (SSI), Temporary Assistance to Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP), and public housing are available. There is the down side of availability, wait lists, and long application processes (Reichman, Corman, & Noonan, 2998).

CF can disrupt social development, which can make it increasingly difficult to maintain and manage their treatments due to the stigma placed on chronic illnesses. Treatment regimens for CF patients are intense and complex, which can make it difficult to remain consistent. It is important to teach adolescents healthy and consistent behaviors for treatment so that they are prepared for transition into adult care. Teaching adolescents healthy behaviors can have the most effective impact if the adolescent understands CF in its entirety. A 2009 study was completed and thirteen of adolescents reported that they do not believe they will have CF for the rest of their lives (Bucks et al., 2009). Therefore, incorporating more education for adolescents with CF and their families can potentially increase the levels of adherence throughout this population.

This is why it is important to maintain a healthy patient-provider relationship. Providers can offer guidance to the family and adolescent to explain CF and what it requires to have a higher quality of life. The psychosocial team can encourage attendance to clinic visits, which can improve the adolescent's knowledge of their disease. By doing this, rates of adherence may increase (Kazmerski et al., 2015). However, it is important to note that increased knowledge does not necessarily produce an improved health status. It does increase the ability of adolescents to learn self-management (Kazmerski et al., 2015).

Adults with CF have reported that clinic visits have held them accountable for their adherence to treatment. Addressing non-adherence is important to identifying barriers that are causing it. However, a study showed that thirty-five percent of centers do not address adherence consistently (Riekert, 2015). By not addressing these concerns, there are missed opportunities to support the family and to offer resources that can increase their adherence.

Some parents and young adults believe that medications are unnecessary and are not benefiting their health (Hanghoj et al., 2014). Side effects of medications and managing treatments at school have been proven to be barriers as well (Hanghoj et al., 2014). Physical symptoms and stigma have been reported to decrease the desire to maintain treatments (Hanghoj et al., 2014). There is also the issue of purposeful non-compliance. Adolescents can potentially underestimate how CF affects them. Adolescents may either forget or state they feel fine without the need for treatment. Non-compliance is also associated with patients not wanting to take medications or treatments in front of their peers for feat of embarrassment (Dodd, 2000). This is another reason that the need for increased knowledge on their disease is important for improved quality of life.

Not only do adolescents need an increase in knowledge about their disease, they also need training when it comes to transition into adult care. Transitions may cause some anxious feelings because adolescents may feel their resources will be less accessible (Al-Yateem, 2013). Therefore, educating them on this topic may decrease some of these concerns.

Transition into Adult Care

Lack of knowledge may affect the patient physically, but it can also affect them when the time comes to transition into adult healthcare. Consistent literature suggests that many patients with CF are concerned about transition and are not being adequately informed on the transition process (Al-Yateem, 2012; Kreindler & Miller, 2013; & Nazareth & Walshaw, 2013). Patients in a pediatric setting rely on parents or caretakers to assist in the process of treatments, clinic appointments, and other daily living tasks. When transition occurs, it is assumed that the patient is autonomous and can appropriately make their personal healthcare decisions (Nazareth & Walshaw, 2013).

One of the main areas of concerns for the pediatric patients is the late start to the introduction of transition. This affects the support, decision-making, and preparation proess for the young adults (Al-Yateem, 2012). Patients become increasingly anxious about the thought of making independent healthcare decisions and being able to manage their care effectively (Nazareth & Walshaw, 2013). Therefore, it is important to educate the parents and patient on the transition process and expectations. By addressing these concerns early on, patients and their families can work on preparing themselves for the transition.

The literature suggests that there is a lack of standardized transition models for patients with CF (Al-Yateem, 2012 & Kreindler & Miller, 2013). However, there are processes and considerations that should be acknowledged prior to transition. For instance, a few characteristics of young adults that are important to note in order to guide the transition process are: readiness, age, knowledge level, and skills (Kreindler & Miller, 2013). There are many families who advocate for their children during the process of transition. A few recommendations provided by families and patients in terms of family-centered assessments are: talk about transition at an early age, explore the challenges by providing resources, and inform the patient on when, how and who will be a part of the transition process (Schlucter, 2014). Further implications should be: allow the patients and families to be involved in the decisions being made, encourage adolescents to be engaged in the decision-making, inform adult care providers of the former pediatric patient, and make sure that the providers and families are in agreement of the decisions being made (Schlucter, 2014). It is important to remember that transitions mean the adolescent will lose relationships and will move to a place that is uncomfortable for some time (Schlicter, 2014).

From the patient's perspectives they had an overall negative feeling towards transition because they were unsure of the process and how it works (Garvey et al., 2012). Their barriers to transition included: lack of a structured plan (Bhaumil et al., 2011). Parents reported feeling more stressed and anxious compared to the patient because they were concerned about the future and the ability to receive adult care services (Kingsnorth, Gall, Beavni & Rigby, 2011). One study found that adult healthcare providers perceived pediatrics as overprotective and pediatrics saw adult care as uncaring (Zhou et al., 2016). Therefore, there needs to be early education for families and effective communication between providers to ensure the transition process is satisfactory.

There is a lack of research on effective readiness models and instruments. A systematic review was conducted to assess the transition readiness tools (Stinson et al., 2013). There are two assessment questionnaires that have been recommended for the transition process. The Transition Readiness Assessment Questionnaire (TRAQ) and the Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) are two tools that assess the adolescent in areas of motivation, maturity, expectations, and readiness (Schwartz et al., 2013 & Zhang et al., 2014). These tools give the clinic team an indication that the adolescent is ready for the process or if they need to be transitioned at a later time.

A 2013 study evaluated the patient's experience post-transition (Chaudhary et al., 2013). The study concluded that patients appreciated a structured program that also integrated the importance of autonomy prior to transition. Patients reported that their access to adult services after transition was a barrier due to the lack of resources available to them (Bhaumik et al., 2011). More research needs to be conducted on the process of transition and how to prepare adolescents appropriately.

Mental Health

When addressing the topic of mental health it is important to note that there are many studies that contradict each other. For instance, some studies suggest that there is a lower quality of life and higher levels of mental health concerns among adolescents while other studies report that mental health outcomes are in line with healthy adolescents (Platten, 2012; Quittner et al., 2008 & Szyndler et al., 2005). Stress from chronic illness has shown to have an impact on a child's mental health. Even with the medical advances that have increased life expectancy, there is still a substantial decrease in life satisfaction (Besier, 2012). For example, strong signs of depression and anxiety have been associated with CF and have contributed to a lower satisfaction of life (Arrington-Sander et al., 2006; Besier, 2012 & Platten, 2013).

There is also evidence that suggests adolescents function as well as their healthy peers. Interestingly, a study showed that adolescents with CF are less likely to develop mental health issues compared to their healthy peers (Szyndler et al., 2005). Reasons for this include: less significant burdens than in previous years and family support (Szyndler et al., 2005). Because of early diagnosis parents have time to cope and will be offered and services in a timely manner.

It is still important for adolescents to maintain peer relationships. Chronic illnesses have the potential to separate an adolescent from their peers during the same time support is needed the most. Social support is important due to the increase in levels of satisfaction, which ultimately improves the quality of life. Adolescents report that they receive most of their relational support from their peers and treatment support from their family members (Barker et al., 2011). Although adolescents recognized that the support was needed, there were still days when the constant questions about treatments and how they were feeling started to become annoying (Barker et al., 2011). A study showed that living in a partnership, regardless of gender, is directly related to satisfaction of life. If the person is surrounded by support and partnership their quality of life should increase. Even though the constant reminder of their disease can be monotonous and annoying; the support from family members and peers is still needed in order to improve their overall quality of life (Barker et al., 2011).

Peer support groups are one way to integrate support for the adolescent. It is important to note that due to specific infection control policies, CF patients cannot be near each other. This poses some issues for support groups to be held. However, online groups have been shown to have positive outcomes on CF patients (Kirk & Milnes, 2016). These support groups encourage participants to be open about their disease and it provides a safe space for parents and patients to express their emotions, concerns and to develop healthy coping styles (Kirk & Milnes, 2006).

For female adolescents the coping style is generally denial, whereas males are more likely to engage in avoidant coping styles (Arrington-Sanders et al., 2006). However, CF does not only affect a child's coping style; it also targets the parents' coping style as well. It is important to take the parents' mental health status into account when working with adolescents because of how influential these roles are on the young patient. When attending to a child that has a chronic illness it can be hard to find time to cope with the diagnosis.

A study found that there are two predominant coping styles that parents utilized. One style was proactive and the other was avoidant (Pfeffer et al., 2003 & Sheehan et al., 2014). Proactive parents were involved, had optimistic perspectives and planned for treatments well whereas avoidant parents used passive and internalizing behaviors (Sheehan et al., 2014). Furthermore, parents are usually unaware that they are carriers of the gene before they conceive a child, therefore it can potentially cause them to feel as though they are at fault. When assessing different types of coping strategies, the most frequent topic is self-blame (Heywood, 2010 & Sheehan et al., 2014).

Avoidant parents were distracted, abused substances, and blamed themselves for their child's illness (Sheehan et al., 2014). Compared to proactive coping styles; avoidant parents reported more problematic child behaviors at mealtimes (Sheehan et al., 2014). The result, adolescents were keeping concerns and problems inside rather than speaking out effectively (Pfeffer et al., 2003 & Sheehan et al., 2014). This suggests that coping styles have an impact on a child's behavior and quality of life (Pfeffer et al., 2003). Those who cope with avoidance are generally non-compliant and less adherent to treatment regimens (Pfeffer et al., 2003).

In contrast, a study showed that adolescents voiced concern about their future. Their fears were about the intense suffering they felt they would go through due to their disease (Riekert et al., 2015). It is important that this population has psychosocial support available to them to maintain healthy coping skills. As a psychosocial team, it is important to advocate for the adolescent. For example, ensuring that the patient is seen individually from time to time is important so the child can voice concerns without the fear of their parents being in the room.

The CF Foundation is now requiring mental health screenings to be completed by all patients with CF that are 12 to 17 (Abbott et al., 2015). This allows the psychosocial team to assess for signs of mental health concerns early on rather seeing a patient that has been impacted severely without anyone knowing (Abbott et al., 2015). Not only does this help catch signs early, it will also help towards future advances for medical care. The CF Foundation and community can assess the needs of the patients based on the results of the screenings (Abbott et al., 2015). This may lead to more positive mental health outcomes and a focus on risk factors with mental health concerns.

CHAPTER III

METHODOLOGY

Children's CF clinic gathered data from completed mental health screenings with 186 patients between February 2016 – March 2017. Administration of these screenings is considered standard of care for pediatric patients with CF. This study utilized secondary data from these mental health screenings and data available through chart reviews in the patient's electronic medical record (EPIC). The study team gathered information regarding the frequency of hospitalizations from February 2016 – March 2017, length of stay, gender, and age. The study then aimed to identify any correlations between the depression and anxiety symptoms reported by patients and frequency of hospitalizations.

Setting

Appropriate International Review Board (IRB) approval was obtained (see Appendix A) from Children's Medical Center and an affiliation agreement was signed by the IRB at Abilene Christian University (see Appendix B). The study is continuing to be researched in the CF clinic at Children's Health Specialty Center in Dallas, Texas. The CF clinic manages outpatient and inpatient care for approximately 400 infants, children, and adolescents. During a patient's visit they meet with providers, nurses, clinical educator, clinical dietician, social workers, medical assistants, respiratory therapists, research coordinators, and the clinic schedulers.

Sample

Inclusion criteria consisted of patients with CF over the age of 12 who were either English or Spanish speaking. As standard of care, verbal consent was given prior to administration of the questionnaires. Based on the guidelines established by the CF Foundation, the mental health screenings were only administered to patients with CF ages twelve and older who voluntarily agreed to take the self-administered assessment. Patients with cognitive impairments, identified either by parent report or standard psychosocial assessment completed by the mental health team, did not complete the self-report measures specifically associated with this study, therefore data collected from adolescents with cognitive impairments was excluded.

Procedure

As per IRB approval, verbal consent was obtained prior to the screening. The 186 mental health screenings completed between February 2016 – March 2017 have been scored. De-identified data from the completed mental health screenings was already stored in a password protected excel file on the CF team's shared drive. The code key was kept in a separate, password protected excel file on the shared drive. Both files were accessible only to study personnel. Chart reviews were then conducted for all patients who participated in the mental health screenings as part of the implementation of the CF guidelines. The mental health screening data that was collected was designed for Quality Improvement (QI) as standard of care in the CF clinic. Mental health screening data was de-identified and each patient's data was assigned a unique identifier. The code key included the patient's name, date of birth, and gender and it was stored in a password protected excel Workbook. The de-identified data from the mental health screenings and medical records review was stored in a separate password protected excel workbook. Both workbooks had protection for read and write access, therefore only those with the password were able to view or edit the information. These excel workbooks were stored on the CF shared drive within Children's database system. The Practice Administrator for the CF clinic was the only person authorized to provide access to this shared drive. Passwords for the Excel workbooks were only shared with members of the research team.

Materials

Two mental health questionnaires were administered to patients with CF that were twelve years old and older based on the CF Foundation guidelines established in 2015. The first questionnaire used in this study was the Patient Health Questionnaire (PHQ-9) (see Appendix C). This screening was developed by Robert L. Spitzer, MD. Kurt Kronke, MD, and Janet B. W. Williams, DSW. This is a nine question, self-administered instrument that scores eacg of the nine Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day). Two studies were conducted to increase the validity of this instrument. The first study involved 3,000 patients in eight primary care clinics and the second study included 3,000 patients in seven obstetrics-gynecology clinics (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 is substantially shorter than most depression measures and is based upon nine criteria that are used for the depression diagnosis within the DSM-IV. When the PHQ-9 is scored and the scores appear to be high; this allows for questions to be asked to officially determine depressive diagnoses based on the DSM-IV criteria and assess the symptom severity (Kroenke, et al., 2001). The scores are assigned to categories of mild, moderate, moderately severe, and severe depression (scores of 5, 10, 15, and 20 respectively). When a patient scores 5-9 the treatment recommendation is to support and educate the patient on depression, 10-14 should be treated with support, watchful waiting, or possible psychotherapy, 15-19 should be treated with antidepressants or psychotherapy, and 20 or higher should also be treated with antidepressants or psychotherapy (Kroenke et al., 2001).

The second instrument used for this study was the Generalized Anxiety Disorder self-report scale (GAD-7) (see Appendix D). A criterion-standard study consisting of 2,740 participants was conducted in fifteen primary care clinics from November 2004 through June 2005. To increase validity of this assessment, the GAD-7 reports were compared to independent diagnoses from mental health professionals (Spitzer, Kroenke, Williams, & Lowe, 2006). The self-report scale includes seven questions about feelings of anxiousness and worry over the last two weeks. The instrument is then scored (0 = not at all sure, 1 = several days, 2 = over half the days, 3 = nearly every day). The results are then assigned to mild, moderate, or severe anxiety (scores of 5, 10, and 15 respectively). Further evaluation of the patient is recommended when the score is 10 or above.

After the clinic social worker or psychologist scored the questionnaires the patient was referred appropriately based on the results. There was no cost to the subjects and no payment for participation in this study. The mental health screenings are a guideline established by the CF Foundation.

Analyses

The results from the PHQ-9 and GAD-7, hospitalizations, length of stay, gender, and age were collected by the Master Social Work candidate and analyzed with assistance from Intern Supervisor, Bonnie Jenkins, LCSW, and Clinic Psychologist, Jamie Becker, PhD for this study. This study required unique identifiers of participants' scores and information. The latest version of SPSS was used for analyzing the data under the supervision of thesis chair, Dr. Wayne Paris, Intern Supervisor, Bonnie Jenkins, LCSW, and Clinic Psychologist Jaime Becker, PhD.

CHAPTER IV

RESULTS

Existing data from 186 patients was collected for this study. All of the patients were diagnosed with Cystic Fibrosis and ranged in age from 12 to 17 years (data not shown). The mean age of the patients was 15 years. There was a near equal distribution of males to females (n=45 and 42, respectively).

Table 1

T-Test Comparison Between PHQ-9 Scores and Gender

	Mean Scores	Significance
Male	3.44	$P<0.05$
Female	5.10	$P<0.05$

A *t-test* was run to determine the comparison between gender and the mean average of the PHQ-9 scores (see Table 1). The results showed that females were significantly more likely to possess depressive symptoms compared to their male counterparts (see Table 1).

Table 2

T-Test Comparison Between GAD-7 Scores and Gender

	Mean Scores	Significance
Male	3.13	NS
Female	6.81	NS

The same test was run to determine if there was a difference between gender and the mean average of the GAD-7 scores. The results showed that there was no significant difference between GAD-7 scores with relation to gender (see Table 2). Further analyses compared gender by number of hospitalizations and mean length of stay. No statistical significance was found (data not shown).

Table 3

ANOVA Comparison of Hospitalizations, Average Length of Stay, and Screening Scores

	Hospitalizations	Length of Stay	Significance
PHQ-9	8.899	.022	NS
GAD-7	.574	.259	NS

To determine if the severity of depression and anxiety were associated with hospitalizations and average length of stay one ANOVA was completed. This required recoding of the PHQ-9 and GAD-7 into their respective ratings for depression and anxiety. The ANOVA did not indicate any statistical significance associated with hospitalizations and length of stay in relation to the level of depression and anxiety (see Table 3). Finally, there was no significant difference in the number of hospitalizations and mean length of stay in relation to the severity of the GAD-7 and PH-9 scores and gender (data not shown).

CHAPTER V

DISCUSSION

Research has shown CF, or any chronic illness, is a risk factor for depression and anxiety. The CF guidelines include four area of mental health care: prevention, screening, clinical assessment, and intervention. By screening children with CF, care centers across the world can begin improving their centers by incorporating the mental health care aspect into their clinic.

The guidelines were established based on a study that assessed over 6,000 patients and 4,000 caregivers among 45 centers in the United States and eight European countries (Quittner et al., 2014). Research has proven that depression and anxiety have a negative impact on CF and overall health. The purpose of this thesis was to determine how depression and anxiety symptoms were associated to hospitalizations among adolescent patients with CF. The findings were consistent in some ways to the existing literature. A review of this information will follow, however, the limitations imposed on this work by the use of existing data must first be discussed.

Ideally, the research team would have included additional demographic data for analyses. The ability to do so was restricted by what was available in the existing data. The data included gender, age, screening scores, and referrals made. This study could be expanded to include severity of the disease, payer status, ethnicity, and region. The reason for this is because each of these areas has shown to have an impact on CF and a person's overall health.

Stroupe and colleagues conducted a study to compare insured and uninsured patients to determine if there was an effect on overall health (Stroupe et al., 2000). The results showed that the "presence of a chronic illness decreased the probability of having adequate coverage by about 10 percent among all individuals and by about 25 percent among single individuals (Stroupe et al., 2000, p.16)." Knowing what the payer status was at the time and how that correlates with overall health and hospitalizations would have been important to note. As the severity of the disease increases, the cost of management significantly increases as well. This is due to increase in medications, hospitalizations and possible travel expenses (Stroupe et al., 2000).

Although there were limitations, there are significant findings to note. This study found that females are more likely to report depressive symptoms compared to their male counterparts. This could be related to the previous literature that discusses how females are more willing to discuss their mental health status. There was no significant relationship in anxious symptoms related to gender, which is not in line with the literature. Literature is consistently providing that depressive and anxious symptoms are more prevalent in females. There was also no significant correlation between mental health symptoms and hospitalizations. This is of interest to note because literature has provided evidence that shows mental illnesses such as depression and anxiety effect overall health. Bennett's Meta-Analytic Review of 60 studies suggests that children diagnosed with a chronic disease are more likely to possess depressive symptoms compared to their physically healthy peers (Bennett, 1994). Therefore, it is important to note the time allowed for this study and the sample size. These factors could be associated with the results that were shown. The team also needs to consider all of the scores when evaluating the results in reference to gender due to evidence that shows males are less likely to report mental health concerns.

There is also evidence that shows significant differences between age and gender when it comes to mental health. A study surveyed school-aged 11 and conducted a post-test at age 15. Of the population surveyed at 11 years of age, 33 percent of males and 37 percent of the females reported feeling sad, unhappy, or low in the month before the survey was distributed (Johansson et al., 2007). There is a gap in the literature that suggests why this occurs. As previously mentioned, studies provide the explanation that females are more open to reporting their mental health symptoms compared to males. Therefore, the findings from these studies and reviews could suggest why the females in our study possessed higher depressive symptoms. It could be attributed to the willingness of the females to be open about how they were feeling. A topic of importance is the difficulty of the subject. The Johansson and colleagues' study that found that 13-year-old adolescents had more of a challenge understanding the concept of mental health compared to the 16-year-olds (Johansson et al., 2007).

In addition to openness, research found that girls are more likely to be knowledgeable of mental health and more expressive of the problems they face (Johansson et al., 2007). Adolescents fear that opening up and talking about their mental health problems will lead them to be treated as an outcast among their peers (Johansson et al., 2007). However, Johansson's study confirmed that girls are more comfortable talking about how they are feeling (Johansson et al., 2007). This could suggest why our study's findings show a significant increase in the PHQ-9 scores among the females.

However, there is still an important question to answer. If females have higher scores of depressive symptoms, then why is there no significance in the length of stay or hospitalizations related to gender? A study concluded that patients diagnosed with a mental health disorder did not necessarily have differing adherence rates than their peers who were not diagnosed with a disorder (White et al., 2009). This could explain why there was no correlation between mental health symptoms and hospitalizations. It is hypothesized that if adherence rates increase then hospitalizations. It is hypothesized that is adherence rates increase then hospitalizations should decrease. There was also limited data that could be used for this study, therefore; the sample size may not have been large enough to see a significant relationship between mental health symptoms and hospitalizations.

Overall, this study possessed a variety of strengths. First, the screenings have proven to possess high reliability and validity. There was a high response rate with the patients who chose to complete the self-report screenings. Finally, the results are consistent with the literature when considering depressive symptoms related to gender. However, there are important limitations to note as well.

Limitations

There are a number of limitations to note when considering this study. First, the study used existing data within the Children's Health CF Clinic's shared drive. This data only contains results from 2016 therefore; this study could only use data from one year. Second, the data was limited because it only contains age, gender, PHQ-9, and GAD-7 screening scores. Our demographic information was limited. Therefore, there were limited factors that could be analyzed. Third, time constraints restricted this study from pursuing other variables that could have been used for this study such as primary payer status, disease severity, ethnicity, and region. Lastly, the instruments used are self-reported, which could be a limitation in itself. The difficulty of the subject matter and how the child was feeling the day of the screening could have an effect on the reports they chose.

Future Implications

When the CF Foundation established the guidelines that all adolescents aged 12 years old and above needed to be screened for mental health symptoms; their goal was to decrease the risk for depression and anxiety. This study's findings can suggest implications for this risk to future clinical teams, parents and caregivers, and peers of adolescents with CF. Although the findings suggest females have a higher rate of reporting depressive symptoms, attention needs to be given to all patients that score moderate to severe symptoms. This study's findings show that there is a great need for mental health resources among the adolescent population. It is also an indicator to the medical staff on who needs to be given priority to be seen first. This data could be used for quality improvement among specialized CF centers across the world. Incorporating mental health care into the CF center could potentially increase the children's overall quality of life.

Being sensitive to the concerns and providing resources can enhance the quality of care given to the patients. They cannot continue to get physically well if their mental health state is not being addressed. Furthermore, these findings can help with the transition to adult care because they provide the medical staff with considerations of where to transition their patients. It is important to note that metal health concerns should be considered a priority when caring for patients with CF.

There is an opportunity for further research utilizing data that has been collected since the development of this study. This research may pose opportunities for further research on why adolescent females are more willing to report their mental health concerns compared to their male counterparts. This translates to the need for developing interventions to address the male population on this issue. Incorporating peer support groups could potentially make the adolescents feel more comfortable talking about their mental health status. However, it is important to note that CF patients cannot be in close proximity to each other due to infection control policies. Therefore, peer support groups may need to be through an external source such as social media or a video chat group. Useful information may be gleaned from screening parents in the future. The CF guidelines suggest screening parents for depression and anxiety symptoms in addition to the adolescents. Because parents have a strong impact on their children, their mental health status may need to be monitored in order to address any concerns that they may have. The sample size could be increased and the data being utilized could be over a larger span of time. This is an ongoing data collection process, which means the screenings that were administered after this study was complete could be used to develop a modification to this study or an additional study in the future.

Conclusion

In conclusion, this study was conducted to determine if mental health status had an effect on overall health. The findings of this study can potentially help contribute to addressing the mental health concerns among the adolescent population who are living with CF. Existing literature is in line with this study in regards to mental health and gender. Therefore, more research needs to be conducted when discussing how to talk to females and males regarding their mental health.

A chronic illness such as CF has a major impact on the patient and caregivers. More attention needs to be given to families and caregivers who are working with adolescents that have CF. High levels of depression and anxiety exist among the family as well. Therefore, the team needs to address all of these concerns before making any changes to the treatment regimen.

The medical team can use this research to make evidence-informed decisions in regards to mental health status of adolescents. This study can potentially increase the literature on mental health related to adolescents and their overall quality of life. By continuing this study, the clinic can find more trends and results, which will lead to improving the mental health care provided by the CF center.

REFERENCES

Al-Yateem, N. (2013). Guidelines for the transition from child to adult cystic fibrosis care. *Nursing Children & Young People, 25*(5), 29-34. Retrieved from http://ezproxy.acu.edu:4655/eds/pdfviewer/pdfviewer?vid=1&sid=969b0aec-1d97-4899-9e70-44a0a8e4d2ba%40sessionmgr4008&hid=4103

Arrington-Sanders, R., Yi, M. S., Tsevat, J., Wilmott, R. W., Mrus, J. M., & Britto, M. T. (2006). Gender differences in health-related quality of life of adolescents with cystic fibrosis. *Health & Quality Of Life Outcomes*, 45-48. doi:10.1186/1477-7525-4-5

Barker, D. H., Driscoll, K. A., Modi, A. C., Light, M. J., & Quittner, A. L. (2012). Supporting cystic fibrosis disease management during adolescence: the role of family and friends. *Child: Care, Health & Development*, *38*(4), 497-504. doi:10.1111/j.1365-2214.2011.01286.x

Barr, H. L., Britton, J., Smyth, A. R., & Fogarty, A. W. (2011). Association between socioeconomic status, sex, and age at death from cystic fibrosis in England and Wales (1959 to 2008): cross sectional study. *BMJ: British Medical Journal*, (7821). 461. doi: 10.1136/bmj.d4662

Bennett, D. S. (1994). Depression among children with chronic medical problems: A meta-analysis. *Journal Of Pediatric Psychology*, 19(2), 149-169. doi:10.1093/jpepsy/19.2.149

Besier, T., Schmitz, T. G., & Goldbeck, L. (2009). Life satisfaction of adolescents and adults with cystic fibrosis: Impact of partnership and gender. *Journal Of Cystic Fibrosis*, 8104-109. doi:10.1016/j.jcf.2008.10.001

Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T., & Forte, J. (2011). Transition for teenagers with intellectual disability: Carers' perspectives. *Journal of Policy and Practice in Intellectual Disabilities,* 8, 53-61. doi: 10.1111/j.1741-1130.2011.00286.x

Bucks, R., Hawkins, K., Skinner, T. C., Horn, S., Seddon, P., & Horne, R. (2009). Adherence to treatment in adolescents with cystic fibrosis: The role of illness perceptions and treatment beliefs. *Journal Of Pediatric Psychology*, *34*(8), 893-902. doi:10.1093/jpepsy/jsn135

Burton, P., Lethbridge, L., & Phipps, S. (2008). Children with disabilities and chronic conditions and longer-term parental health. *Journal Of Socio-Economics*, 37(Behavioral Dimensions of the Firm Special Issue), 1168-1186. doi:10.1016/j.socec.2007.01.032

Chaudhary, S., Keaton, M., & Nasr, Z. (2013). Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatric Pulmonology*, 48, 658-665. doi: 10.1002/ppul.22647

Cohen-Cymberknoh, M., Shoseyov, D., Kerem, E. (2011). Managing cystic fibrosis: Strategies that increase life expectancy and improve quality of life. *American Journal of Respiratory and Critical Care Medicine, 183*(11). Retrieved from http://www.atsjournals.org/doi/full/10.1164/rccm.201009-1478CI#_i1

Denny, S., de Silva, M., Fleming, T., Clark, T., Merry, S., Ameratunga, S., & ... Fortune, S. A. (2014). The prevalence of chronic health conditions impacting on daily functioning and the association with emotional well-being among a national sample of high school students. *Journal Of Adolescent Health*, *54*(4), 410-415. doi:10.1016/j.jadohealth.2013.09.010

Dodd, M. E., & Webb, A. K. (2000). Understanding non-compliance with treatment in adults with cystic fibrosis. *Journal Of The Royal Society Of Medicine* (Supplement), *93*(38), 1-8. Retrieved from http://ezproxy.acu.edu:4655/eds/pdfviewer/pdfviewer?vid=1&sid=61004985-cf4a-48c8-ba37-acc38c989055%40sessionmgr4006&hid=4103

Douglas, T., Green, J., Park, J., Turkovic, L., Massie, J., & Shields, L. (2016). Psychosocial characteristics and predictors of health-care use in families of young children with cystic fibrosis in Western Australia. *Journal Of Paediatrics And Child Health*, *52*(1), 34-39. doi:10.1111/jpc.13011

Everhart, R. S., Fiese, B. H., Smyth, J. M., Borschuk, A., & Anbar, R. D. (2014). Family Functioning and Treatment Adherence in Children and Adolescents with Cystic Fibrosis. *Pediatric Allergy, Immunology & Pulmonology*, *27*(2), 82-86. doi:10.1089/ped.2014.0327

Garvey, K. C., Finkelstein, J. A., Laffel, L. M., Ochoa, V., Wolfsdorf, J. I., & Rhodes, E. T. (2013). Transition experiences and health care utilization among young adults with type 1 diabetes. *Patient Preference & Adherence*, 7761-768. doi:10.2147/PPA.S45823

Grossoehme, D., Filigno, S., & Bishop, M. (2014). Parent routines for managing cystic fibrosis in children. *Journal Of Clinical Psychology In Medical Settings*, *21*(2), 125-135. doi:10.1007/s10880-014-9396-1

Hanghøj, S., & Boisen, K. A. (2014). Self-reported barriers to medication adherence among chronically ill adolescents: A systematic review. *Journal Of Adolescent Health*, *54*(2), 121-138. doi:10.1016/j.jadohealth.2013.08.009

Heywood, J. (2010). Childhood disability: ordinary lives for extraordinary families. *Community Practitioner*, *83*(4), 19-22. Retrieved from http://ezproxy.acu.edu:4656/eds/pdfviewer/pdfviewer?vid=1&sid=5bc2c8b2-804c-44b7-a1a1-a68293a1dba4%40sessionmgr102&hid=114

Higham, L., Ahmed, S., & Ahmed, M. (2013). Hoping to live a 'normal' life whilst living with unpredictable health and fear of death: Impact of cystic fibrosis on young adults. *Journal Of Genetic Counseling*, *22*(3), 374-383. doi:10.1007/s10897-012-9555-1

Johansson, A., Brunnberg, E., & Eriksson, C. (2007). Adolescent girls' and boys' perceptions of mental health. *Journal Of Youth Studies*, *10*(2), 183-202. doi:10.1080/13676260601055409

Kazmerski, T. M., Miller, E., Abebe, K. Z., Matisko, J., Schachner, D., & Spahr, J. (2015). patient knowledge and clinic attendance in adolescent patients with cystic fibrosis. *Pediatric Allergy, Immunology & Pulmonology*, *28*(2), 107-111. doi:10.1089/ped.2014.0475

Kingsnorth, S., Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child: Care, Health & Development, 37*(6), 833-840. doi:10.1111/j.1365-2214.2011.01294.x

Kirk, S., & Milnes, L. (2016). An exploration of how young people and parents use online support in the context of living with cystic fibrosis. *Health Expectations*, 19(2), 309-321. doi:10.1111/hex.12352

Knudsen, K., Pressler, T., Mortensen, L., Jarden, M., Skov, M., Quittner, A., … Boisen, K. (2016). Associations between adherence, depressive symptoms and health-related quality of life in young adults with cystic fibrosis. *Springerplus, 5*(1). Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4967055/

Kreindler, J. L., & Miller, V. A. (2013). Cystic fibrosis: addressing the transition from pediatric to adult-oriented health care. *Patient Preference & Adherence*, 71221-1226. doi:10.2147/PPA.S37710

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606–613. doi: 10.1046/j.1525-1497.2001.016009606.x

McCoyd, J. M., Akincigil, A., & Eun Kwang, P. (2010). Pediatric disability and caregiver separation. *Journal Of Family Social Work*, *13*(3), 251-268. doi:10.1080/10522151003716353

Modi, A. C., & Quittner, A. L. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: What gets in the way? *Journal Of Pediatric Psychology*, *31*(8), 846-858. doi:10.1093/jpepsy/jsj096

Modi, A. C., Lim, C. S., Yu, N., Geller, D., Wagner, M. H., & Quittner, A. L. (2006). A multi-method assessment of treatment adherence for children with cystic fibrosis. *Journal Of Cystic Fibrosis*, 5177-185. doi:10.1016/j.jcf.2006.03.002

Nazareth, D., & Walshaw, M. (2013). Coming of age in cystic fibrosis - transition from paediatric to adult care. *Clinical Medicine*, *13*(5), 482-486. Retrieved from http://ezproxy.acu.edu:4655/eds/pdfviewer/pdfviewer?vid=1&sid=2e937d56-2316-4486-b50b-ff45ba72cf70%40sessionmgr4008&hid=4103

O'Connor, G. T., Quinton, H. B., Kneeland, T., Kahn, R., Lever, T., Maddock, J., & ... Swartz, D. R. (2003). Median household income and mortality rate in cystic fibrosis. *Pediatrics*, *111*(4), e333. Retrieved from http://pediatrics.aappublications.org/content/111/4/e333.full

O'Haver, J., Moore, I., Insel, K., Reed, P., Melnyk, B., & Lavoie, M. (2010). Parental perceptions of risk and protective factors associated with the adaptation of siblings of children with cystic fibrosis. *Pediatric Nursing*, *36*(6), 284-291. Retrieved from http://ezproxy.acu.edu:4656/eds/pdfviewer/pdfviewer?vid=1&sid=fcd0764f-aca2-400f-83b8-e2195bef0567%40sessionmgr120&hid=114

Pfeffer, P., Pfeffer, J., & Hodson, M. (2003). Review: The psychosocial and psychiatric side of cystic fibrosis in adolescents and adults. *Journal Of Cystic Fibrosis*, 261-68. doi:10.1016/S1569-1993(03)00020-1

Pinquart, M., Shen, Y. (2010). Depressive symptoms in children and adolescents with chronic physical illness: An updated meta-analysis. *Journal of Pediatric Psychology, 36*(4). Retrieved from http://jpepsy.oxfordjournals.org/content/36/4/375.full.pdf+html

Platten, M., Newman, E., & Quayle, E. (2013). Self-Esteem and its relationship to mental health and quality of life in adults with cystic fibrosis. *Journal Of Clinical Psychology In Medical Settings*, *20*(3), 392-399. doi:10.1007/s10880-012-9346-8

Quittner, A. L., Goldbeck, L., Abbott, J., Duff, A., Lambrecht, P., Sole, A., … Barker, D. (2014) Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: Results of the international depression epidemiological study across nine countries. *Thorax*, 69. Retrieved from http://www.fibrosisquistica.org.ar/images/profesionales/thorax-2014-prevalencia_de_depresion_y_ansiedad.pdf

Reichman, N., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal & Child Health Journal*, *12*(6), 679-683. doi: 10.1007/s10995-007-0307-z

Riekert, K. A., Eakin, M. N., Bilderback, A., Ridge, A. K., & Marshall, B. C. (2015). Original Article: Opportunities for cystic fibrosis care teams to support treatment adherence. *Journal Of Cystic Fibrosis*, 14142-148. doi:10.1016/j.jcf.2014.10.003

Schechter, M. S., McColley, S. A., Silva, S., Haselkorn, T., Konstan, M. W., & Wagener, J. S. (2009). Association of socioeconomic status with the use of chronic therapies and healthcare utilization in children with cystic fibrosis. *The Journal Of Pediatrics*, *155*(5), 634-639. doi:10.1016/j.jpeds.2009.04.059

Schlucter, J. (2014). Patient- and Family-Centered Transitions From Pediatric to Adult Care. *Pediatric Nursing*, *40*(6), 307-310. Retrieved from http://ezproxy.acu.edu:4656/eds/pdfviewer/pdfviewer?vid=1&sid=24e327c7-04bc-4204-9b64-981602f6a1c8%40sessionmgr120&hid=114

Schwartz, L. A., Brumley, L. D., Tuchman, L. K., Barakat, L. P., Hobbie, W. L., Ginsberg, J. P., & Deatrick, J. A. (n.d). Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatrics*, *167*(10), 939-946. doi: 10.1001/jamapediatrics.2013.2223

Segal, T. Y. (2008). Adolescence: what the cystic fibrosis team needs to know. *Journal Of The Royal Society Of Medicine* (Supplement), *101*(7), S15-S27. doi:10.1258/jrsm.2008.s18005

Sheehan, J., Hiscock, H., Massie, J., Jaffe, A., & Hay, M. (2014). Caregiver coping, mental health and child problem behaviours in cystic fibrosis: A cross-sectional study. *International Journal Of Behavioral Medicine*, *21*(2), 211-220. doi:10.1007/s12529-013-9289-y

Smith, J., Cheater, F., Bekker, H. (2013). Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. *Health Expectations*. 18, 452-474. doi: 10.1111/hex.12040

Spitzer, R., Kroenke K., Williams, J. & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder. *Arch Intern Med*. Retrieved from http://www.integration.samhsa.gov/clinical-practice/GAD708.19.08Cartwright.pdf

Spitzer, R., Kroenke K., Williams, J., & Lowe, B. (2006). Patient health questionnaire. Retrieved from https://www.med.umich.edu/1info/FHP/practiceguides/depress/phq-9.pdf

Stinson, J., Kohut, S. A., Spiegel, L., White, M., Gill, N., Colbourne, G., & ... Kaufman, M. (2014). A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *International Journal Of Adolescent Medicine And Health*, *26*(2), 159-174. doi:10.1515/ijamh-2013-0512

Stroupe, K. T., & Kinney, E. D. (2000). Does chronic illness affect the adequacy of health insurance coverage? *Journal Of Health Politics*, 25(2), 309. Retrieved from http://ezproxy.acu.edu:4656/eds/pdfviewer/pdfviewer?vid=1&sid=3ff60224-6cd6-432c-9123-911db0a182db%40sessionmgr103&hid=114

Szyndler, J. E., Towns, S. J., van Asperen, P. P., & McKay, K. O. (2005). Psychological and family functioning and quality of life in adolescents with cystic fibrosis. *Journal of Cystic Fibrosis*, 4135-144. doi:10.1016/j.jcf.2005.02.004

White, T., Miller, J., Smith, G., & McMahon, W. (2009). Adherence and psychopathology in children and adolescents with cystic fibrosis. *European Child & Adolescent Psychiatry*, 18(2), 96-104. doi:10.1007/s00787-008-0709-5

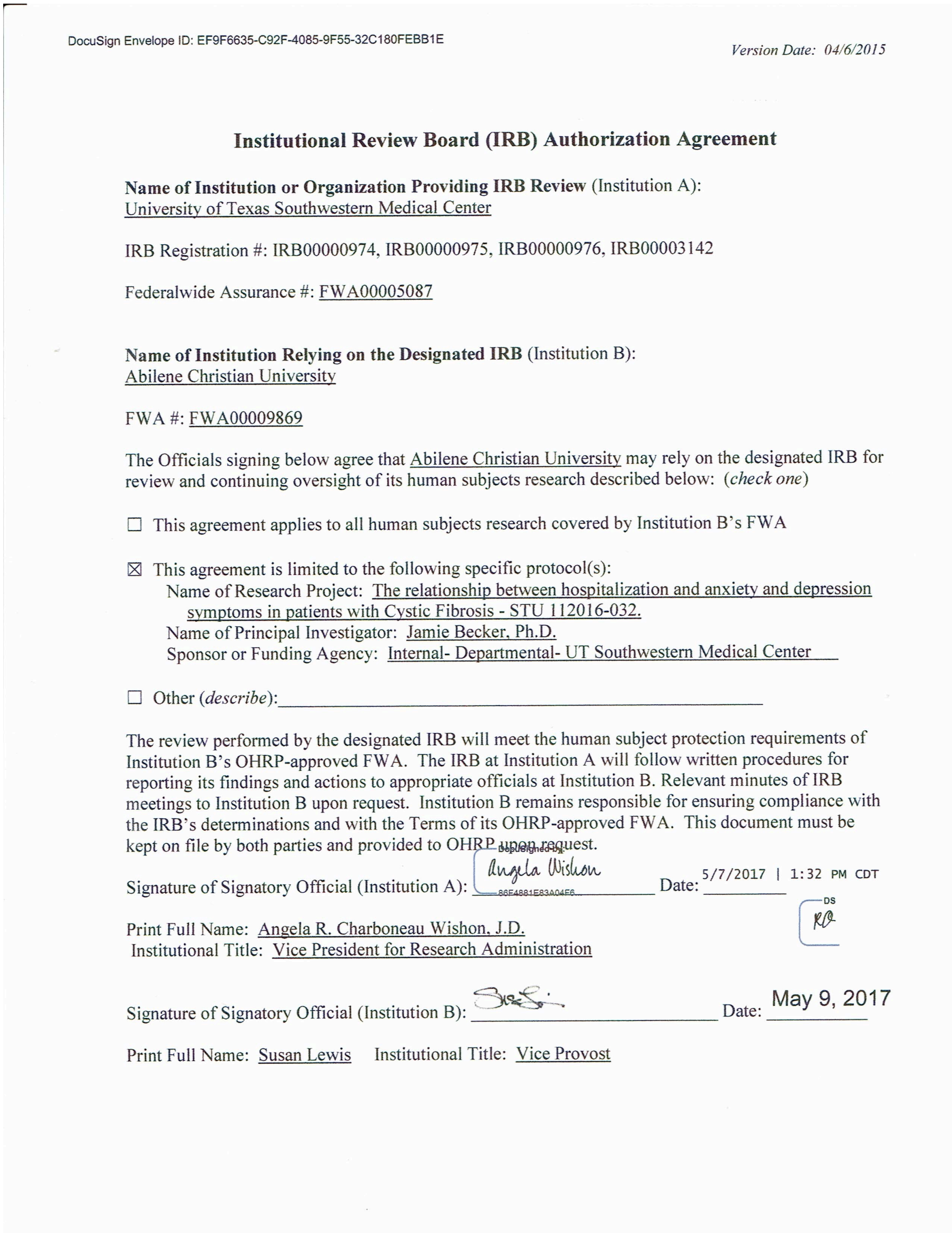
Wong, L. H., Chan, F. W., Wong, F. Y., Wong, E. L., Huen, K. F., Yeoh, E., & Fok, T. (2010). Original article: Transition care for adolescents and families with chronic illnesses. *Journal Of Adolescent Health*, 47540-546. doi:10.1016/j.jadohealth.2010.04.002

Zhang, L. F., Ho, J. W., & Kennedy, S. E. (2014). A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatrics*, 144. doi:10.1186/1471-2431-14-4

Zhou, H., Roberts, P., Dhaliwal, S., & Della, P. (2016). Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review. *Journal Of Clinical Nursing*, *25*(21-22), 3113-3130. doi:10.1111/jocn.1332

APPENDIX A

ACU IRB Approval Letter



DocuSign Envelope ID: EF9F6635-C92F-4085-9F55-32C180FEBB1E

Version Date: 04/6/2015

Institutional Review Board (IRB) Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution A):
University of Texas Southwestern Medical Center

IRB Registration #: IRB00000974, IRB00000975, IRB00000976, IRB00003142

Federalwide Assurance #: FWA00005087

Name of Institution Relying on the Designated IRB (Institution B):
Abilene Christian University

FWA #: FWA00009869

The Officials signing below agree that Abilene Christian University may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (*check one*)

☐ This agreement applies to all human subjects research covered by Institution B's FWA

☒ This agreement is limited to the following specific protocol(s):
Name of Research Project: The relationship between hospitalization and anxiety and depression symptoms in patients with Cystic Fibrosis - STU 112016-032.
Name of Principal Investigator: Jamie Becker, Ph.D.
Sponsor or Funding Agency: Internal- Departmental- UT Southwestern Medical Center

☐ Other (*describe*):____

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

DocuSigned by:
Signature of Signatory Official (Institution A): Angela Wishon
86F4881E83A04F6... Date: 5/7/2017 | 1:32 PM CDT

DS
RO

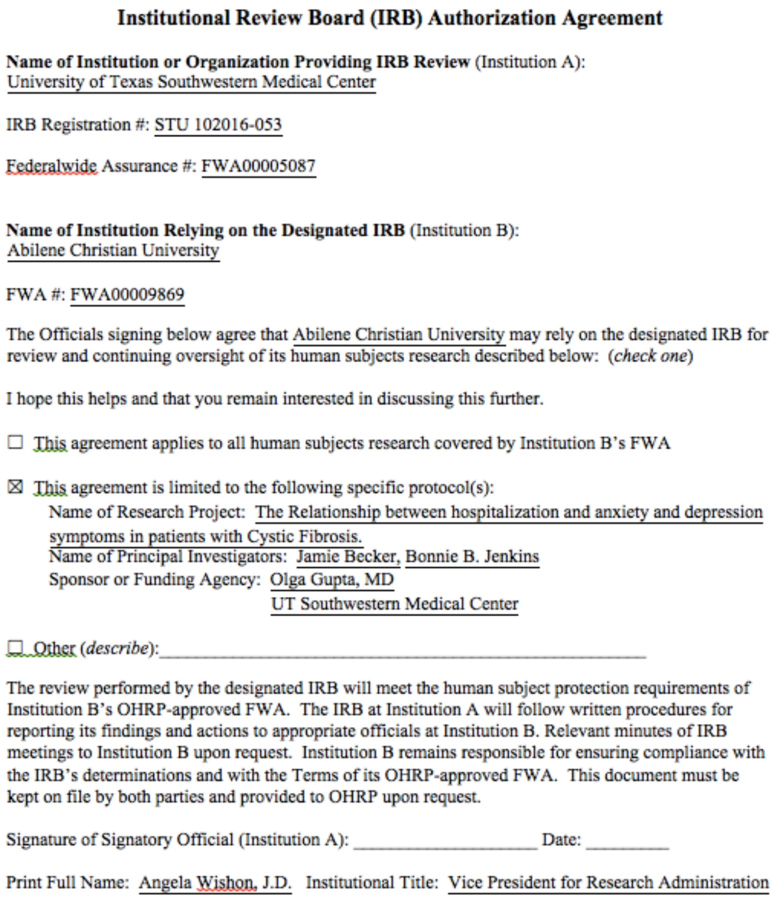
Print Full Name: Angela R. Charboneau Wishon, J.D.
Institutional Title: Vice President for Research Administration

Signature of Signatory Official (Institution B): ________________ Date: May 9, 2017

Print Full Name: Susan Lewis Institutional Title: Vice Provost

APPENDIX B

IRB Approval Letter



Institutional Review Board (IRB) Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution A):
University of Texas Southwestern Medical Center

IRB Registration #: STU 102016-053

Federalwide Assurance #: FWA00005087

Name of Institution Relying on the Designated IRB (Institution B):
Abilene Christian University

FWA #: FWA00009869

The Officials signing below agree that Abilene Christian University may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (*check one*)

I hope this helps and that you remain interested in discussing this further.

☐ This agreement applies to all human subjects research covered by Institution B's FWA

☒ This agreement is limited to the following specific protocol(s):
Name of Research Project: The Relationship between hospitalization and anxiety and depression symptoms in patients with Cystic Fibrosis.
Name of Principal Investigators: Jamie Becker, Bonnie B. Jenkins
Sponsor or Funding Agency: Olga Gupta, MD
UT Southwestern Medical Center

☐ Other (*describe*):____

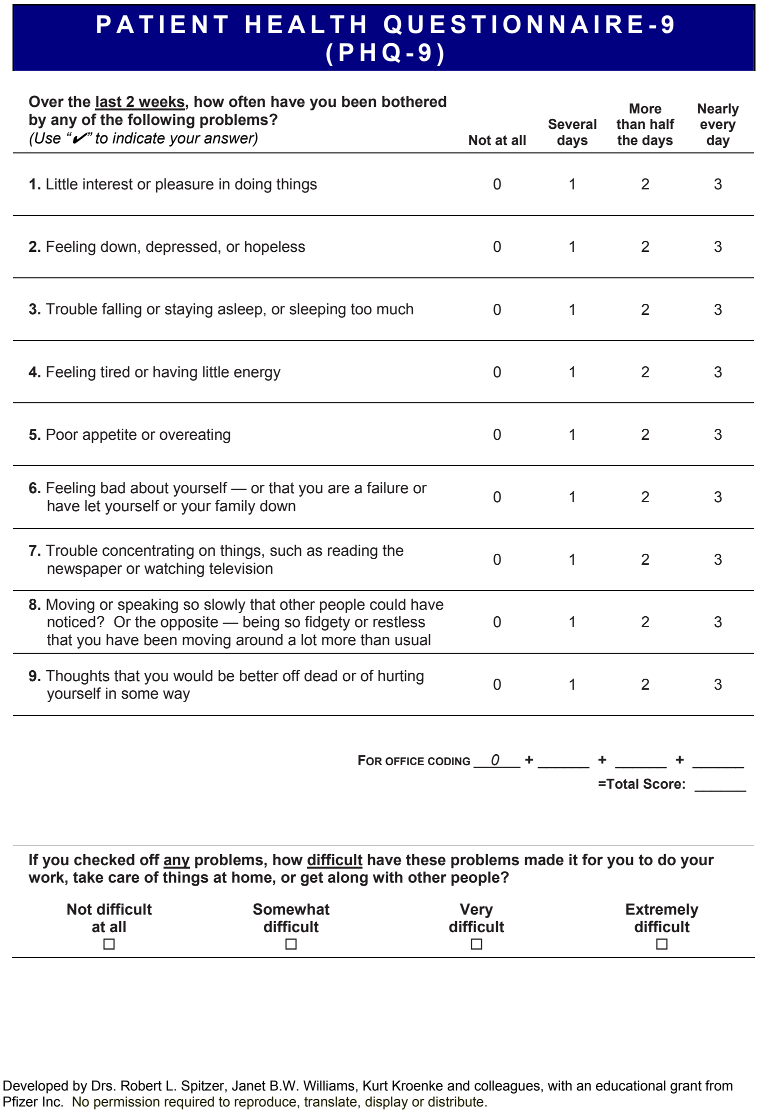
The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution A): ____________________ Date: _________

Print Full Name: Angela Wishon, J.D. Institutional Title: Vice President for Research Administration

APPENDIX C

Patient Health Questionnaire (PHQ-9)



PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING __*0*__ **+** ______ **+** ______ **+** ______

=Total Score: ______

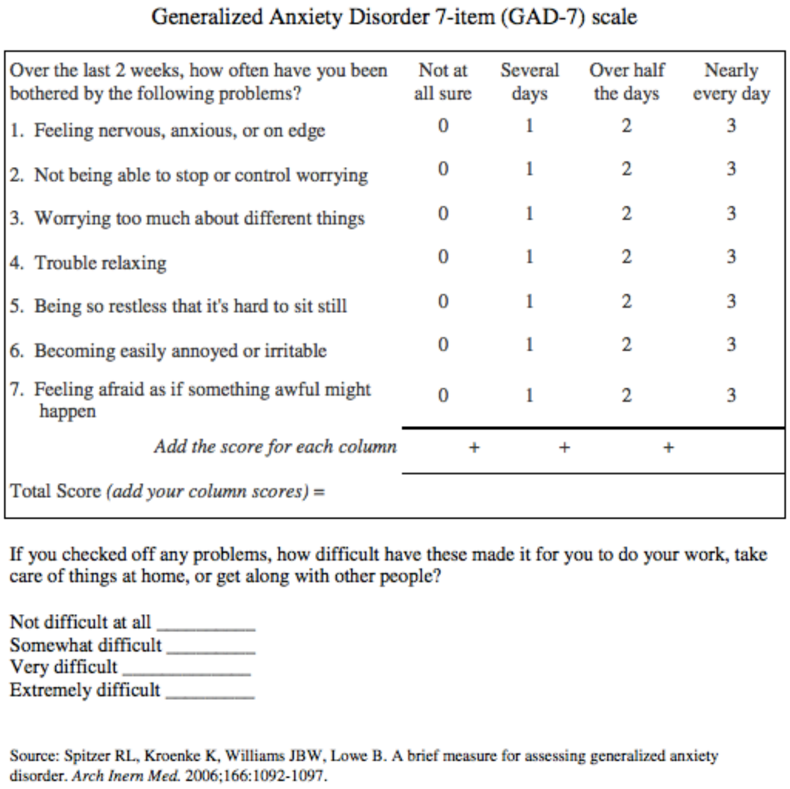
If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
☐	☐	☐	☐

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

APPENDIX D

Generalized Anxiety Disorder 7-Item Scale (GAD-7)



Generalized Anxiety Disorder 7-item (GAD-7) scale

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Add the score for each column	+	+	+	
Total Score *(add your column scores)* =				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all __________
Somewhat difficult _________
Very difficult _____________
Extremely difficult _________

Source: Spitzer RL, Kroenke K, Williams JBW, Lowe B. A brief measure for assessing generalized anxiety disorder. *Arch Inern Med.* 2006;166:1092-1097.