

Comprehensive Evaluation- Single Subject Design

Amy L. McCaughan

Saint Leo University

This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), under grant #T72MC00002/University of Florida Pediatric Pulmonary Center/PI: Wagner, for total grant amount of \$1,718,631. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government

Introduction

Cystic Fibrosis (CF) is a genetic disease that affects the lungs and reduces the ability to breathe over time (Cystic Fibrosis Foundation, n.d.). Not only does CF affect the respiratory functions, but the digestive and reproduction systems also (Cystic Fibrosis Foundation, n.d.). CF causes thick, sticky mucus to build up in the lungs and digestive tract, which leads to troubled breathing and the inability to digest food properly (National Heart, Lung, and Blood Institute, n.d.). It is also the most common life-threatening illness among Caucasians (Grossman, Zughier, Lui, & Tangpricha, 2012). Cystic Fibrosis is a genetic defect in the cystic fibrosis transmembrane conductance regulator (CFTR) gene (Cystic Fibrosis Foundation, n.d.). If a person only inherits one of these defective genes, then they are considered a carrier because they will not suffer from the disease. If a person inherits both these genes (one from the mother and one from the father), then they will have the full onset of cystic fibrosis and must be treated for the disease the rest of their life.

There are approximately 30,000 diagnosed CF cases in the United States and approximately 70,000 cases worldwide (Cystic Fibrosis Foundation, 2017). There are numerous treatments that a person with CF must complete daily to maintain their health. These treatments include, but are not limited to, using a vest to loosen mucus from the lungs daily, taking enzymes to assist in digestion and absorption of food, use of supplemental nutrients, and breathing treatments (Ferreira, n.d.). Due to the difficulty in gaining and maintaining weight, a gastrointestinal tube may be placed into the patient's stomach to add much needed nutrients through a tube feeding (Lucile Packard Children's Hospital Stanford, n.d.). Patients may have to be hospitalized to have an endoscopy and lavage to have mucus suctioned out of the patient's lungs (Mayo Clinic,

2016). On average, the patients at Shands pediatric CF clinic are hospitalized twice a year for “tune-up”, which entails procedures such as an endoscopy to clear their lungs (Horky, 2017). Patients with CF have outpatient clinic appointments every three months and the average visit takes approximately two and a half to three hours (Miney, 2018). The reason for the length of the appointment is the number of specialties each patient sees each visit. The CF foundation requires that the patient see a doctor, a nurse, a respiratory therapist, a psychologist, a nutritionist, and a social worker (Mullally, 2018). Since Shands is a teaching hospital, the visit can also include being seen by a pharmacist and various students assigned to each specialty. Labs also must be completed within certain time frames, which can result in a lab technician being involved in some appointments. If the patient has a GI tube, then the patient will usually have an appointment with a gastrologist on the same day.

Visiting the clinic every three months is only one aspect of treatment. Patients spend on average four hours a day treating their CF (Mullally, 2018). The patients are required to complete a vest treatment two to four times a day. The patient wears a vest that emits vibrations and those vibrations loosen the mucus in the patient’s chest so that the patient can cough the mucus up and out of their lungs. The patients are also required to take treatments with a nebulizer. A nebulizer is a machine in which a liquid medication, such as steroids, is turned into a vapor that the patient can inhale. The patients are also required to double their caloric intake because their body is unable to process all the food that they eat, and their body burns more calories than the average person. Enzymes are taken before each meal and snack to assist with the process of breaking down food into energy, but enzymes can only aid so much in the digestion of food. Their bodies also require more energy to fight infections and to cough on a

regular basis. If the client does not cough, then the mucus continues to build up in their lungs and could require a hospitalization to manually remove some of the mucus.

Visiting the outpatient clinic every three months and completing hours of treatment at home can take a toll on both the child and the parent. Although pulmonary doctors can treat CF patients, most parents prefer to be seen at a CF center. There are only 3 pediatric CF centers in Florida- Nemours Children's clinic in Jacksonville and Orlando and UF Shands clinic in Gainesville (Mullally, 2018). When one factors in that most families have more than one child, that numerous families only have one parent struggling to make ends meet, the heavy responsibility of staying focused on their child's CF treatments, and the level of poverty that reigns with many of the families at the CF outpatient clinic at Shands, the result can be a lack of adherence to treatments by the patient and their families. Due to the length of every outpatient CF visit, some families choose not to come to their appointments, which can result in higher hospitalization rates.

Although CF is a severe enough diagnosis on its own, there are some co-occurring disorders related to CF. Type 3 diabetes, arthroplasty, and osteoporosis are a few common disorders associated with CF (Naehrig, Chao, & Naehrich, 2017). Anxiety and depression are also common co-occurring disorders (Besier & Goldbeck, 2012). ADHD is emerging as a common co-disorder with CF (Cohen-Cymerknoh, et al., 2015). One study tested 122 CF patients over the age of six to determine if they met the criteria for ADHD (Cohen-Cymerknoh, et al., 2015). The result was that 55 patients (45%) met some of the criteria for ADHD and 20 patients (16%) met all the criteria for ADHD. These results display that children with CF have a higher rate of ADHD than in normal population (Cohen-Cymerknoh, et al., 2015). Taking into consideration the higher rate of ADHD and the combined amount of time needed to complete treatments and

attend all medical appointments, the ability to address and manage behavior to increase the speed and efficiency of outpatient appointments become a prominent need in the CF clinic at Shands.

The capability to address the symptoms of ADHD in children with CF is very important. The inability to stay focused during treatments at home can cause patients to miss or only partially complete scheduled treatments. Children with CF tend to miss more school than other children their age due to their hospitalizations and any reduction in the ability to stay focused due to ADHD can cause further delays in their education. The inability to stay focused and engaged in their outpatient appointments can cause the appointment to extend in time and result in a higher stress level in the parent and an increased frustration with the patient. Therefore, the treatment of ADHD, in conjunction with the treatment of CF, can result in quicker appointments and, hopefully, will have the added benefit of encouraging the child to stay focused and willing to complete at home treatments, which could possibly have an impact on lowering the number of hospitalizations that the patient experiences every year.

Introduction to the Patient

This single subject design involves a seven-year-old Caucasian female patient who has CF and has also been diagnosed with ADHD. The patient currently lives with a medical foster mother and has been with her medical foster mother since September of 2017. Prior to removal from her mother's care, the patient had lived with her mother, two siblings, and mom's boyfriend. The patient and her siblings were removed from their mother's care due to substance abuse on the part of the mother and for domestic violence perpetrated towards the mother by her boyfriend. The patient's other two siblings went to a different foster home because they do not have CF and do not require life sustaining treatments that the patient does.

The patient has been with the CF clinic at Shands since her birth. She was diagnosed with ADHD shortly after she entered kindergarten. Notation by the CF team displays that the patient has always struggled with staying focused and engaged when at her outpatient clinic appointments and she has shown defiance and lack of being focused regarding her treatments at home. Although the removal from her mother has strengthened these behavioral issues, the case notes reflect that the inability to stay focused has always been an issue.

Overview of the Agency

The Pediatric Pulmonary Clinic is located at UF Health Shands in Gainesville, Florida. Senator William Shands dreamed of building a teaching hospital and those dreams came to fruition on October 20, 1958 (UF Health, n.d.). The University of Florida and Shands hospital began a relationship in which UF students could achieve their medical degrees and begin their careers in a hospital that made teaching and learning a part of their healthcare services. UF Health Shands is a not-for-profit hospital that focuses on the education and quality of service to those who are of need in healthcare. The Pediatric Pulmonary Clinic (PPC) was developed in 1979 (UF Pediatrics Pulmonary Division, 2018). The PPC includes several specialties- asthma, CF, lung transplants, and sleep disorders, just to name a few. The PPC clinic consists of doctors, nurses, social workers, nutritionists, and other staff needed to offer complete care to their patients (see Appendix A).

UF Health Shands is very definitive regarding their mission, vision, and goals. Their mission is simple- patient care, research, education, and community service (UF Health, n.d.). Their vision is “together we strive to create unstoppable momentum toward the goal of improving individual and community health through discovery, clinical and translational science and technology, exceptional education and patient-centered, innovative, high-quality health care.

This is our vision as we harness The Power of Together” (UF Health, n.d.). Their values are “accountability, diversity, excellence, innovation, integrity, teamwork, and trust” (UF Health, n.d.).

There are numerous stakeholders when it comes to UF Health Shands. The patients are the biggest stakeholders. Without patients, there would be no population to provide services to. Insurance companies are also stakeholders. If the hospital does not meet the requirements for the insurance companies, then they will go out of business. The University of Florida is a stakeholder because Shands is the hospital they send their students to work at. The hospital is accredited by the Joint Commission. The Joint Commission is a not-for-profit agency that is made up of doctors, nurses, administrators, and educators that inspect a hospital every three years to ensure that the hospital is following laws, regulations, and providing the highest quality of care to their patients (The Joint Commission, 2016). Therefore, the accreditation board is a form of stakeholder in Shands. There is also a board of directors, which are also stockholders, in which the hospital is accountable to (see Appendix B).

The theoretical foundation of Shands is patient centered care. Patient centered care involves the ability to assess the needs of the patients and offer appropriate and qualitative care in a timely fashion, integrating care through multi- disciplinary teams and collaboration, and identifying and using resources in the most efficient manner possible, and restructuring managerial roles so that the highest level of support and care is given to the employee’s and patients (Fiorio, Gorli, & Verzillo, 2018). There must be a balance with patient-centered care. The hospital must be able to streamline their services so that they are able to treat all patients that come through their doors. There is a delicate balance between focusing on the patients needs and quality of care and the ability to meet the needs of the community.

There are numerous interventions put into place by Shands. Putting the medical services aside, there is the psychiatric hospital, numerous social workers in all departments, and there is a department that specifically goes into the community to offer opportunities for healthcare and research. With the medical aspect taken into consideration, there are numerous services offered. Pediatrics, oncology, gastrologists, optometrists, a dental clinics, and many other specialties can be found at Shands.

Evaluation of Pediatric CF Clinic

For a patient to be admitted into the pediatric CF program at Shands, they either need to be referred by their primary care provider (PCP) or they must have tested positive in their newborn screen test. Once the patient has been referred to the CF clinic, an appointment is then scheduled. Hospital records and PCP medical records requested and are entered into the patient database. At the first appointment, a detailed history is taken. Then, the nurse at the CF clinic adds the patient into the CF foundation register (Mullally, 2018). This registry tracks the patient and their families throughout their care. If the patient moves or chooses to attend a different CF center, the patient information is tracked in the CF foundation database.

The pediatric CF clinic also tracks the number and frequency of hospitalizations of their patients, the average length of appointment times, the number of missed or cancelled appointments, the number of times replacement equipment is ordered (i.e.: a patient requisition for a new vest or a new nebulizer), and the number of referrals for other providers, and who the referrals were made to (Mullally, 2018). Since Shands is a teaching hospital, various students track information also. For instance, the nutritionists might track the number of patients who have had GI tubes surgically placed or the number of PediSure cans given out during each clinic. The pharmacy students might track the number of patients who have opted to take one drug over

another in their treatment of CF. The family care partners might track what support systems the families have put into place and evaluate the efficiency of such systems. Information collected is done through medical records, clinic appointments, tracking charts, satisfaction surveys, and students who are used to gather and collect information for evaluation purposes.

Since CF is not curable, the information collected is used to streamline and improve the efficiency and quality of care provided to the patients through the CF clinic. The CF foundation uses collected information for their registry and in their accreditation of Shands as a CF center. The information collected is also used to track and assess the causes of hospitalizations, to pinpoint the needs of the patients, to assist in determining the factors that affect treatments at home, and factors that the CF team can use to assist the patients and their families in creating supportive services to put into place to assist with overcoming the barriers that either impede treatment or to assist in treating any co-occurring disorders the patient might be experiencing.

The information gathered is dissected by the PPC department head and higher management both within the hospital and the school. The information is passed along to both Shands and University of Florida for evaluation of the program and of the continuing education of the providers and students in the CF clinic. Recently, the information has been used to change the schedule CF clinic days. Up until July 1st, the CF clinic was conducted every Tuesday. After evaluation of appointment history, the clinic now runs every other Tuesday. The goal is to streamline the services so that the patients are not waiting to be seen in clinic for hours and that the CF doctor's, called pulmonologists, can be used to assist in services in other clinics (i.e. the asthma clinic). Since this change came about at the beginning of the new fiscal year, not enough data has been gathered to determine if the goals of efficiency and lessened wait time have been achieved.

On a wider scale, the information gathered is also used by the CF foundation so that Shands can be accredited as a CF center. It is also used by the Joint Commission to assist in the accreditation of the hospital, insurance companies use it to determine the billing and distribution of funds for services, and it is used for grants that the hospital receives. For instance, one grant that the PPC receives funds the UF PPC training program (Horky, 2017). The US Department of Health and Human Services created the Health Resources and Services Administration. This administration oversees several agencies, one being the Maternal Child and Health Bureau. UF then receives funds from this bureau “to recruit and train health care professionals who will be future leaders in the culturally competent, community based, family centered care of children with respiratory disorders” (Horky, 2017). The PPC grant encompasses numerous specialties- disparity, healthcare administration, pharmacology, social work, psychologists, nutritionists, and medical students in the hopes of creating a new wave of specialists that are patient-centered and culturally competent in their specialty and to be trained professionals that can serve for the greater good of society (Health Resources and Services Administration- Maternal and Child Health, n.d.). There are six PPC training sites across the country. The PPC program has a yearly conference in which students, past and present, can present posters and lead round table discussions on the numerous topics that affect healthcare and leadership in the medical field.

The goals of the pediatric CF clinic are to reduce the number of hospitalizations through routine care and treatments, to assist the families in meeting all the patient’s medical needs, and to provide high quality and efficient care. Information is gathered through patient files and data collection from doctors and students. The information is evaluated and reported to the department chair on a quarterly basis. The information collected reflects the amount of time each patient spends in a clinic appointment, the number and causes of hospitalizations, the number of

referrals made to other providers or outside services and monitors the number of patients seen at the CF clinic and how it compares to patient transfers in and out to other CF centers.

Client Strengths and Limitations

The purpose of this study is to implement a behavior tool to assist in reducing the length of time spent at each outpatient CF clinic appointment, specifically regarding the current CF patients that suffer from the co-occurring disorder of ADHD. The specific patient selected for this single subject research design has several strengths and limitations. This patient has been seen by the Shands CF clinic since her birth, so the physicians and various professionals involved in her care have been involved her entire life. The physicians have full disclosure to all her medical records and referrals that have been made for her. They have a working relationship with the patient's family. The child has been seen by a psychologist at Shands who has diagnosed her with ADHD. She is currently taking medication for the treatment of her ADHD. There are also some limitations to using her for this study. She was removed from her mother's care in September of 2017. The jolt of being moved away from her mother, whom she has lived with her entire life, and being placed in an unfamiliar foster care home could have negatively impacted the patient's behavior. The anxiety and fear that can be involved in such a major change could cause the patient to act out, or even to appear to vastly increase in ADHD symptoms, even though those symptoms could be trauma based rather than behaviorally or medically based. Since the patient is in a medical foster home, and there are fewer medical foster homes to serve children in need, the chances of other children being moved in and out of the home are greater than the average foster home and these changes can also affect the behavior of the patient. The child has been hospitalized numerous times in the past year. The higher than average amount of hospitalizations can create a frustration that increases the patient's inability to

stay focused during her outpatient clinic visits. Finally, her mother has a solid relationship with the foster mom and often attends the CF clinic appointments with the patient. The possibility that the confusion with the relationships with both the mother and the foster mother could cause an increase of behavioral issues born out of anxiety and confusion rather than ADHD.

Hypothesis and Variables

The hypothesis is that if a behavioral reward system is put into place during outpatient CF clinic appointments, the length of time of each clinic appointment will be reduced by one-third of the time previously spent at outpatient clinic appointments. The independent variable is the behavior chart created to modify the patient's behavior and the dependent variable is the patient's ability to focus on each professional that the patient meets with (doctor, social worker, nutritionist, etc.). This research is important to determine if the diagnosis of CF and ADHD can result in a higher rate of lack of treatment adherence, an increase in hospitalizations, and longer clinic visits that can have a direct effect on the length and quality of life of a CF patient.

Literature Review

Cystic Fibrosis (CF) is a disease that requires daily treatment with the goal of managing the symptoms and their impact on the patient's life. Adherence to treatment can be difficult as it applies to children due to shorter attention spans and behavioral issues (Butcher & Nasr, 2014). The regimen of treatment can be hefty- daily enzymes before each meal and snack, vest treatments, nebulizer treatments, and medications all play into the individualized treatments that the patient is required to complete daily. Each CF patient is encouraged to double their daily caloric intake due to the extra energy the body needs to battle illness and to work the mucus out

of their lungs and to participate in exercise daily, which will increase the flow of oxygen and assist in stimulating the mucus loose, so it can be coughed out.

When the medical aspect of treatment is put aside, CF can dramatically affect the behavior, mental health, and relationships of the patient to those around them. As patients move through their developmental stages from birth into adulthood, CF alters how they develop. For instance, the first couple years the child develops a bond with their parent/caregiver. Children ages three to five begin to grasp the concept of their treatment but not yet be able to understand the idea of death and how it possibly threatens their life. Ages five to nine begin to grasp the concept of death and are being conditioned to the necessity of their treatments. Ages ten and older begin the cycle of peer pressure and the learning curve of developing relationships, which can dramatically be affected by the time spent on treatments, appointments, and hospitalizations. Add in the fact that it is common for those diagnosed with CF to miss more school than their peers, then it makes sense that those with CF suffer with other physical and mental disorders (Anton-Paduraru, Ciubara, & Miftode, 2015).

Numerous barriers can cause an interruption, or discontinuance of, daily treatment. Time management skills, the presence of other siblings in the home, the quality of the relationship between the parent and the child, and oppositional behaviors all play a part regarding non-compliance of home treatments (Grossochme, Filigno, & Bishop, 2014). Family dynamics, financial stability, family support, and educating the family about the necessity of treatment must be considered when addressing non-compliance of treatment with a patient and their family.

ADHD is a common disorder in school age children and affect approximately 5% to 12% of the population (Sesar, Dodaj, & Sesar, 2014). ADHD is marked by an inability to stay focused and/or hyperactivity and impulsivity (Sesar, Dodaj, & Sesar, 2014). ADHD has a negative

impact on school performance, social relationships, and reduces the ability to exercise emotional control (Forner, et al., 2016). Those who have been diagnosed with ADHD can suffer from a lack of development of social skills and self-regulation, which can lead to an increased risk of cigarette smoking, depression, and a difficulty of adjustment to adolescence (Fiorio, Gorli, & Verzillo, 2018).

One area of study that is emerging is the co-occurring disorder of CF and ADHD. Although research on the correlation of these two diagnosis is slim, the study of the possibility of a relationship between the two is beginning to intrigue the scientific community. Since those who are diagnosed with CF have a higher rate of missing days of the school year due to illness and hospitalizations, having the added diagnosis of ADHD can be disastrous. Having ADHD reduces the ability to stay focused in the classroom when the patient can attend school, it increases the length of time completing at home treatments due to the lack of the ability to maintain attention and stay still during vest and nebulizer treatments, and it could increase the friction between the patient and their parent/caregiver due to the struggle to stay focused on the completion of treatments. The development of self-care skills early on in CF patients with ADHD can cause an increase of treatment adherence and result in better health outcomes than those in which the ADHD is not acknowledged and treated (Spitzer, Legare, Patel, Toselli, & Livingston, 2018). There are few studies that delve into the area of co-occurring disorders of CF and ADHD. Those that have been conducted call for more research into this area to determine the validity and reliability of the current research.

Methodology

The measures used would be simple seeing how the CF clinic already monitors the length of the patient's visit based on the period of when the patient checked in at the front desk to be seen

to when they are checked out by the receptionist at the end of their visit. When the patients have been led to an examination room, the various staff for each specialty then use a magnetic board to represent which specialty is in with which patient and at what time. The staff can also notate what time they first saw the patient and follow up with the time that they ended their visit (see Appendix C). The compilation of information regarding length of visit would be posted every quarter so that the clinic staff could see the average length of the outpatient clinic appointment.

Sampling

For this study, the participant selected in a seven-year-old Caucasian female who has already been diagnosed with ADHD and is currently taking psychotropic medication to treat the ADHD symptoms. Based on the results in this case study, the sampling criteria could be more defined using patients ages three to ten and who either have already been diagnosed with ADHD or shows enough symptoms that the CF clinic psychologist would recommend that they participate in the behavioral program to assist in reducing the length of time of each outpatient visit. Informed consent will be collected by the parents/guardians prior to any collection of information regarding the specific case study and, if pursued, the patients that might qualify for the behavioral study to be implemented in outpatient clinic with more patients (see Appendix D).

Data Collection

Since this study is currently limited to one patient, the information collected will be specific. Times will be collected from when the patient checks in to when the patient checks out, providers will notate the times they spend with the patient in the examining room, a survey will be taken from the parents/guardians at the end of their visit, and the clinical notes from each visit will be analyzed and rated as to the time management of each appointment (if recorded by the

provider). A behavioral chart, which lists the expectation of behavior based on the provider, will be given at the beginning of the visit (see Appendix E). If the patient meets all the criteria, then the patient will turn the chart in for a prize at the end of their visit. Data will first be collected on three visits before the intervention of the behavior chart is put into place and for three visits after the intervention of the behavior chart was put into place. The data pre- and post- intervention will then be analyzed and compared to determine if the patient has engaged more during the visit and if the engagement has reduced the amount of time spent at each outpatient clinic appointment.

Validity and reliability will be subjective at the beginning of this single case study. Each provider determined what behavioral factors they wish to see in the patient during the clinic visit. One issue that could appear is that every provider can interpret behavior differently. For example, one doctor might prefer that the child sit still during their time in the examination room whereas another doctor would find that sitting still during their examination is unrealistic. After the case study is conducted, prior to extending this behavior chart to other qualifying patients, a debriefing will need to be conducted among the CF team as to whether the criteria they have previously set out need to be modified based on varying symptoms displayed in clinic by patients or the process in which results are collected.

Research Design

Since this project only includes one patient, it is considered a single case study. The study will consist of an A-B-A design. The current length of the outpatient clinic appointment time will be recorded in the first three appointments, the behavioral chart intervention will be used in visits four through six, and then the intervention will be removed, and times will be recorded in visits seven through nine. The study will be exploratory in nature as there are few studies that link the

co-occurring disorder of CF and ADHD. There are no studies that address these co-disorders and its effect of appointment times at outpatient clinic appointments.

The patient was selected by the providers at the CF clinic. A patient recommendation was asked for by the social worker and the patient was selected by the providers who deal directly with the patient at their clinic appointment.

Results

The goal of this proposal is to improve the efficiency and length of outpatient CF clinic appointments with patients that have been diagnosed with the co-occurring disorder of ADHD. With the selected patient, the CF team aims to reduce the length of the clinic visit and to provide supportive services to assist the foster mom in the patient's participation of CF treatments at home. Since this patient is hospitalized more often than the average twice a year, on average four to five times a year, the research will monitor the effect of the interventions and how the amount of hospitalizations could be reduced if the behavioral intervention put into place assists the patient in compliance during clinic appointments and home treatments.

If, over time, there is a recorded difference in the length of the appointment, the goal is to then put this measure into place with other patients in the CF clinic. The results will need to be evaluated over a minimum period of one year. A survey will be given to the foster mom, or if returned to the mother, then the mother will complete the survey, to gather feedback of the behavior they have observed during clinic visits (see Appendix F).

Discussion

Although the life span of those diagnosed with CF have improved dramatically in the past thirty years, the length of outpatient clinic visits and the burden of daily at home treatments can

create a barrier to the health of the child and could potentially result in a higher number of ER visits and hospitalizations. One way to reduce the barrier and resistance to treatment is to shorten the time of appointments in the outpatient CF clinic. To achieve this goal, the providers must work efficiently with the staff and patients to streamline services within the clinic. Working with children who have ADHD creates a resistance to the goal of efficient appointments and the ability to comply with their home treatments. If the CF team can work together to assist in keeping the child focused during clinic visits, then there is a chance that the parent/guardian will be able to take the tools used in clinic and apply them to assist in the compliance of completing at home treatments.

The CF team will appreciate the ability to see patients quicker if the patients are able to stay focused while they are in the examination room. The clinic can be affected by reducing the time spent at appointments, it could open the physician's schedule to see more patients within the PPC department, it could increase the patient's and family's satisfaction with the CF clinic, which will have a positive impact on patient satisfaction when it comes to accreditation. The hospital will also be impacted by the reduction of pay for hourly employees as services are streamlined and increased in efficiency. A proposed timeline and early budget for this study can be found in Appendix G.

Limitations

There are several limitations to this study. First, a single case study does not represent the entire population of patients in the CF clinic. Although the possible link between CF and ADHD is currently becoming an area of future research, that does not automatically place every CF patient into the position of being distracted or inattentive during their appointment. Second, the removal from her mother's care could have created a traumatic reaction that mirrored as

symptoms of ADHD but are not biologically based. Third, the rotation of doctors that flex in and out of the CF clinic could cause an inconsistency regarding the behavioral expectations that are listed on the chart. Since there several doctors in the PPC division, the physician's take rotations working in the CF clinic. Finally, since this project was developed by a SW intern, one of the permanent staff in the CF clinic would need to take responsibility in ensuring the use of the behavior chart, ordering the prizes, collect data, and oversee the debriefing with the CF clinic staff regarding the application of said intervention and the refining of the intervention as needed.

References

- Anton-Paduraru, D. T., Ciubara, A., & Miftode, E. (2015). Psycho-Social aspects in children with cystic-fibrosis. *Revista De Ceretare Si Iterventie Sociala vol.48*, 204-215. DOI:
- Besier, T., & Goldbeck, L. (2012). Growing up with cystic fibrosis: Achievement, life satisfaction, and mental health. *Quality of Life Research: An International Journal of Quality of Life, Aspectsof Treatment Care, and Rehabilitation* 21(10), 1829-1835. DOI: 10.1007/s11136-011-0096-0
- Butcher, J. L., & Nasr, S. Z. (2014). Direct observation of respiratory treatments in cystic fibrosis: Parent-child interactions relate to medical regimen adherence. *Journal of Pediatric Psychology* 40(1), 8-17. DOI: 10.1093/jpepsy/jsu074
- Cohen-Cymerknoh, M., Tanny, T., Blau, H., Kaosh, D., Mussaffi, H., Nir, V., . . . Berger, I. (2015). 300 Prevalence and characteristics of attention deficit hyperactivity disorder (ADHD) in patients with cystic fibrosis (CF). *Journal of Cystic Fibrosis*, 297-300. DOI: 10.7759/cureus.3048
- Cystic Fibrosis Foundation*. (2017, July 1). Retrieved from www.cff.org: <https://www.cff.org/About-Us/The-CF-Foundation-by-the-Numbers.pdf>
- Cystic Fibrosis Foundation*. (n.d.). Retrieved from www.cff.org: <https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/>
- Ferreira, L. M. (n.d.). *Cystic Fibrosis News Today*. Retrieved from www.cysticfibrosisnewstoday.com: <https://cysticfibrosisnewstoday.com/living-with-cystic-fibrosis/>

- Fiorio, C. V., Gorli, M., & Verzillo, S. (2018). Evaluating organizational change in healthcare: The patient-centered hospital model. *BMC Health Services Research* 18(95), 2-15. DOI: 10.1186/s12913-018-2877-4
- Forner, C. B., Miranda, B. R., Foreta, I. B., Castellar, R. G., Diago, C. C., & Casas, A. M. (2016). ADHD symptoms and peer problems: Mediation of executive function and theory of mind. *Psicothema* 29(4), 514-519. DOI: 10.7334/psicothema2016.376
- Grossman, R., Zughier, S., Lui, S. L., & Tangpricha, V. (2012). Impact of vitamin D supplementation on markers of inflammation in adults with cystic fibrosis hospitalized for pulmonary exacerbation. *European Journal of Clinical Nutrition*, 1072-1074.
- Grossochme, D. H., Filigno, S. S., & Bishop, M. (2014). Parent routines for managing cystic fibrosis in children . *Journal of Clinical Psychology in Medical Settings* vol.21, 125-135. DOI: 10.1007/s10880-014-93996-1
- Health Resources and Services Administration- Maternal and Child Health*. (n.d.). Retrieved from www.mchb.hrsa.gov: https://mchb.hrsa.gov/training/project_info.asp?id=374
- Horky, S. (2017, July 11). (A. McCaughan, Interviewer)
- Lucile Packard Children's Hospital Stanford*. (n.d.). Retrieved from www.stanfordchildrens.org: <http://www.stanfordchildrens.org/en/topic/default?id=feeding-your-child-with-cystic-fibrosis-90-P02932>
- Mayo Clinic*. (2016, October 13). Retrieved from www.mayoclinic.org: <https://www.mayoclinic.org/diseases-conditions/cystic-fibrosis/diagnosis-treatment/drc-20353706>

Miney, A. (2018, May 22). (A. McCaughan, Interviewer)

Mullally, C. (2018, July 3). (A. McCaughan, Interviewer)

Naehrig, S., Chao, C.-M., & Naehrich, L. (2017). Cystic fibrosis diagnosis and treatment. *Deutsches Aerteblatt International*, 564-574.

National Heart, Lung, and Blood Institute. (n.d.). Retrieved from www.nhlbi.nih.gov:

<https://www.nhlbi.nih.gov/health-topics/cystic-fibrosis>

Sesar, K., Dodaj, A., & Sesar, D. (2014). Attention deficit/hyperactivity disorder and comorbid disorders in 6-12 year old girls and boys. *Pediatrics Today* 10(1), 28-42. DOI: 10.5457/p2005-114.86

Spitzer, N., Legare, T. B., Patel, P., Toselli, N., & Livingston, F. (2018). The prevalence and effect of comorbid cystic fibrosis and attention deficit hyperactivity disorders on hospitalizations. *Cureus*.

The Joint Commission. (2016, July 8). Retrieved from www.jointcommission.org:

https://www.jointcommission.org/facts_about_the_joint_commission/

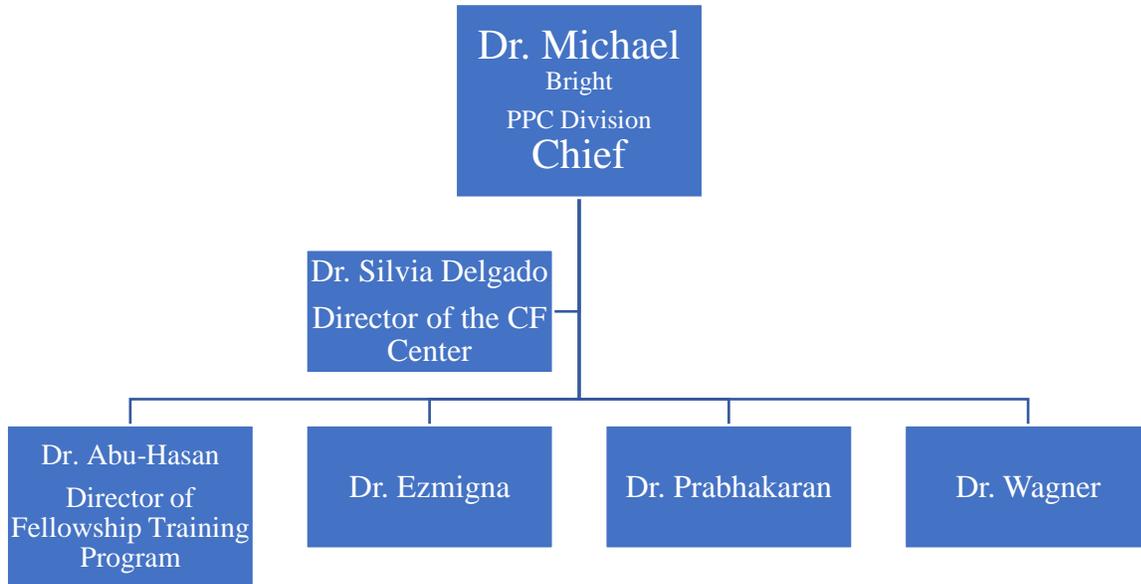
UF Health. (n.d.). Retrieved from www.ufhealth.org: <https://ufhealth.org/about-william-shands>

UF Pediatrics Pulmonary Division . (2018, June 11). Retrieved from

www.pulmonary.pediatrics.med.ufl.edu: <https://pulmonary.pediatrics.med.ufl.edu/>

Appendix A

PPC Staff at UF Shands



Staffing information can be found at <https://pulmonary.pediatrics.med.ufl.edu/about-us/faculty-staff/>

Note- All physicians listed on the PPC website do not serve in the CF clinic. All PPC doctor's who routinely practice in the CF clinic are notated above

Appendix B

UF Shands Board of Directors

Officers:

- Gale King, Chair, Columbus, OH
- Anita Zucker, Vice Chair
- Thomas Mitchell, Executive Vice President, Gainesville
- Joseph A. Mandernach, Associate Vice President, Gainesville
- Karen Rice, Associate Vice President, Gainesville
- David M. Christie, Treasurer, Gainesville
- Susan Goffman, Secretary, Gainesville

Board of Directors:

S. Andrew Banks, Kelley A. Bergstrom, Carol M. Brewer, Shannon E. Carbone, J. Rex Fariior, III, W. Kent Fuchs, Elizabeth D. Gadsby, Joe Glover, Scott G. Hawkins, Joseph Hernandez, Rhonda D. Holt, Linda P. Hudson, Gale V. King, Beth A. McCague, Diane McFarlin, Linda C. McGurn, Mike. V. McKee, Joelen K. Merkel, M. Ann O'Brien, Louis H. Oberndorf, Rahul Patel, Jon Pritchett, James H. Pugh, Jr., Jody R. Swanson, Gwynne A. Young, Anita G. Zucker

Appendix C

The patient board in the CF clinic is set up as follows:

	Patient name	Patient name	Patient name	Patient name
Physician				
Care Coordinator (nurse)				
Nutritionist				
Psychology				
Social Work				
Respiratory Therapist				
Pharmacy				
Lab				

The chart above is a replica of the dry erase board that is position in the clinic office where the CF staff conduct their appointments. Each specialty has a magnet that reflects their specialty. Before the provider goes in the examination room, they place the magnet for their specialty under the patient’s name and use a dry erase maker to notate the time they went to the exam room. When they are done, they remove their magnet and write the time they left the room. The magnet system prevents interruption while the provider is in the room and the recording of the time assists in monitoring the time each specialty spends with each patient during their clinic visit.

Appendix D

IMPLIED CONSENT TO PARTICIPATE IN A RESEARCH BEHAVIOR MODIFICATION PROJECT

Participant: _____

Title of Study: Behavioral Modification in CF Clinic Appointments

Purpose of Study: To determine if a behavior chart implemented during clinic appointments can decrease the time spent at the appointment

Procedures: Allow your child to interact with providers, engage in expected behaviors, and to receive a reward if the goals have been met

Benefits: There are no benefits to participate

Risks: There are no risks imposed outside of daily life

Costs/incentives: Although there are no cost to you to participate in this study, there is the possibility of a prize given if the participate meets all goals set out in the behavior chart by each provider

Confidentiality: No identifying information will be collected, and all information collected will be kept confidential.

Use of information: The researcher is only collecting this information as a part of a study to determine behavioral interventions put in place to decrease the wait time at the CF clinic appointment

Participation: You may choose to decline from this study at any time.

By signing below, you are agreeing to:

- Allow your child to be given a behavioral chart at the beginning of each visit
- Allowing each provider to explain the behavioral expectations
- Allowing your child to be given a prize at the end of the clinic visit if your child has met all behavioral expectations at the end of the clinic visit. If your child does not meet all the expectations, then no prize will be offered
- You agree to participate in this study for one year. At the end of the year, you will have the option to continue to be a part of this study or you can withdraw. You may withdraw from this study at any time by submitted a written letter of withdrawal

Name/Relationship

Date

Witness

Date

Appendix E

	<p><u>Pulmonologist</u></p> <ul style="list-style-type: none"> • Answer questions, • take deep breaths and cough 	
	<p><u>Care Coordinator</u></p> <ul style="list-style-type: none"> • Complete throat swabs • Complete labs • Answer questions 	
	<p><u>Nutritionist</u></p> <ul style="list-style-type: none"> • Make eye contact • Answer questions 	
	<p><u>Psychology</u></p> <ul style="list-style-type: none"> • Make eye contact • Answer questions • Fill out papers (if asked) 	
	<p><u>Social Work</u></p> <ul style="list-style-type: none"> • Make eye contact • Answer questions 	
	<p><u>Respiratory Therapist</u></p> <ul style="list-style-type: none"> • Listen • Follow directions 	



*A sticker will be placed in the third column if the patient met all behavioral goals for each provider

Appendix F

Parent/Guardian Survey of Behavioral Expectations

Child's Name: _____ Date: _____

Survey prior to introduction of behavior chart: _____

Survey after introduction of behavior chart: _____

Each rating should be considered in the context of what is appropriate for the age of your child.

Frequency Code: 0 = Never 1 = Occasionally 2 = Often 3 = Very Often

- | | | | |
|---|---|---|---|
| 1. Has difficulty paying attention to what the provider is saying | 1 | 2 | 3 |
| 2. Responds quickly to questions being asked | 1 | 2 | 3 |
| 3. Able to follow instructions after being asked | 1 | 2 | 3 |
| 4. Does seem to listen when being spoken to | 1 | 2 | 3 |
| 5. Is easily distracted during the examination | 1 | 2 | 3 |
| 6. Fidgets throughout the visit | 1 | 2 | 3 |
| 7. Refuses to comply with instructions | 1 | 2 | 3 |
| 8. Moves about for most of the visit rather than sitting down | 1 | 2 | 3 |
| 9. Is easily annoyed throughout the visit | 1 | 2 | 3 |
| 10. Does not instigate altercations with siblings during visit | 1 | 2 | 3 |

Appendix G

Projection	Completion
<ol style="list-style-type: none"> 1. Administer survey to parent in Jan. visit- document appointment length for visits during Jan. April, July 2. Administer behavioral chart during visits Oct., Jan., April 3. Re-administer survey in April Appointment after use of behavior chart 	
<ol style="list-style-type: none"> 1. Approval to buy novelties for treasure box http://www.orientaltrading.com/web/search/searchMain?keyword=bulk toys&category=Toys%c%-Games -Novelties- \$250/ per year 2. Add \$2,400.00 to social worker’s pay to oversee this project. SW may use student interns to assist in data collection and follow up surveys with parent 	

- The budget and timeline listed above is to be put into application if the behavior chart decreases the time spent in the CF clinic appointment with the selected case study