Increasing Self-Management of Cystic Fibrosis Through the Use of Smartphone App Technology

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Increasing Self-Management of Cystic Fibrosis Through the Use of Smartphone App Technology

Abstract
Cystic Fibrosis (CF) is a chronic and progressive genetic disease affecting the body's transportation of salt and water through cells. Those with CF experience various respiratory, reproductive, and digestive complications. 30,000 people in the US are currently living with CF. Research indicates poor adherence to treatment regimens results in life-threatening consequences and poor long-term health outcomes. Compliance is particularly low in teenagers and young adults. The identification of current smartphone technology and applications are examined and the advantages they have in increasing self-management in the CF population. A new app specifically targeted for those with CF is introduced.

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INCREASING SELF-MANAGEMENT OF CYSTIC FIBROSIS THROUGH THE USE OF
SMARTPHONE APP TECHNOLOGY

By

Jenna Coon

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ABSTRACT

Cystic Fibrosis (CF) is a chronic and progressive genetic disease affecting the body's transportation of salt and water through cells. Those with CF experience various respiratory, reproductive, and digestive complications. 30,000 people in the US are currently living with CF. Research indicates poor adherence to treatment regimens results in life-threatening consequences and poor long-term health outcomes. Compliance is particularly low in teenagers and young adults. The identification of current smartphone technology and applications are examined and the advantages they have in increasing self-management in the CF population. A new app specifically targeted for those with CF is introduced.

Keywords: Cystic Fibrosis, Smartphone Apps, Self-Management, CF diet
Increasing Self-Management of Cystic Fibrosis Through the Use of Smartphone App Technology

Introduction

The smartphone industry has been growing steadily as the general public has embraced the use of smartphones and smartphone applications (apps). Children and teenagers are becoming increasingly fluent with this technology and using smartphones at younger ages now more than ever. However, there has been much debate as to whether this is good or bad. What if smartphones were used to increase compliance in populations suffering from chronic conditions, specifically respiratory chronic conditions? What if apps could be designed and used to help improve the health of our children? With the incidence of chronic disease growing in our nation’s children and co-morbid respiratory conditions rising (Kanter, 2010), we can use this technology as a resource to control and ultimately improve the health outcomes of those affected with chronic respiratory disease.

Cystic Fibrosis (CF) is a chronic and progressive inherited disease affecting the body’s transportation of salt and water through cells. Ultimately, individuals with CF experience various respiratory, reproductive, and digestive complications. Research has shown that compliance within the CF population is vital to satisfactory patient outcomes (Ernst, Johnson, & Stark, 2010). Furthermore, poor adherence can have serious life-threatening consequences. In order to promote self-management in individuals with chronic conditions, the use of smartphone app technology is being examined.

Description of Problem

According to the Cystic Fibrosis Foundation (CFF), about 30,000 people in the United States are living with CF. Additionally, 1,000 people are newly diagnosed with CF every year.
CF is commonly diagnosed within the first two years of life and occurs in one in every 3500 newborns making it the most common life threatening autosomal recessive disease in the United States (Farrell et al., 2008). CF is a fatal condition as it affects several body systems including the respiratory, reproductive, and digestive systems. CF is notorious for thick and sticky mucus and very salty sweat as a result of a defect in the CFTR gene. This particular gene is instrumental for the transportation of salt and water into and out of body cells (National Institutes of Health [NIH], 2013). This defect limits proteins in their productivity, which causes thick and sticky mucus. Normally, mucus is a slippery, watery substance and serves as a protective coating preventing our organs from becoming dried out or infected. However, when the mucus thickens it makes the perfect reservoir for bacteria growth, which is why patients with CF are prone to repeated lung infections (NIH, 2013). The majority of these lung infections are chronic. In addition to the respiratory system, the reproductive system of those with CF is also affected. Approximately, 98% of men with CF are infertile. While in the uterus, there is abnormal development of the vas deferens of the fetus, which prevents the transportation of sperm to penis (Marcoelles et al., 2011). Contrastingly, women with CF are usually able to conceive because their reproductive tracts are anatomically normal (Ahmad, Ahmed, & Patrizio, 2013). However, some women with CF experience reduced fertility due to thick mucus in the cervix providing a barrier for sperm to penetrate the egg (Kreda, Davis & Rose, 2012, p. 11).

CF significantly affects the digestive system and close monitoring of diet is crucial for individuals with this condition. Thick mucus causes problems for ducts within the body, mainly the pancreas. Blocked ducts of the pancreas prevent digestive enzymes from reaching the small intestine and without them the intestines are not able to absorb fats and proteins as efficiently. Inability to absorb fats and proteins can lead to malnutrition and vitamin deficiencies (NIH,
As a result, individuals with CF are required to take supplemental digestive enzymes before meals to help facilitate digestion. The number of supplemental digestive enzymes required before a meal is calculated based on the fat and protein content of the meal. Needless to say, calculating enzyme dosages and recording strict intake/output daily can be quite daunting. First time parents are at a disadvantage especially. Not only are these parents learning how to properly care for a newborn, but they are also learning how to properly care for the complex needs of a child with CF.

**Genetic Testing & Counseling**

All states screen newborns for CF using a genetic or blood test. The genetic test indicates CF by the presence of a defective CFTR gene, while a blood test will show whether or not the newborns pancreas is working properly. The most reliable diagnostic test for CF is the quantitative pilocarpine iontophoresis, otherwise known as a “sweat test”. This test is the gold standard for the diagnostic testing of CF. Essentially this test measures the amount of salt in the infant’s sweat. This test is particularly valuable because it is painless and simple. The test stimulates sweat production using a sweat-producing chemical over the infant’s forearm. An electrode is then used to provide an electrical current, which has the potential to cause a tingling sensation. Sweat is then collected on a pad and analyzed (Martiniano, Hoppe, Sagel, & Zemanick, 2014, p. 236). A high level, indicative of CF would be considered equal to or over 60 mmol/L in infants. It should be noted that patients with CF secrete up to four times the normal amount of sodium chloride (NIH, 2013). A sweat test should not be performed until after two weeks of age because healthy newborns’ sweat chloride concentrations gradually decrease over the first weeks of life (Farrell et al., 2008, p. 8). If the newborn screening test (NBS) is positive and the infant also has a raised sweat chloride test, the infant will receive a diagnosis of CF, even if the infant
does not display any clinical manifestations. However, a positive newborn screening test alone is not enough to diagnose the infant with CF because the newborn screening test’s purpose is solely to identify those infants who should undergo further testing.

**Treatment & Self-Management Regimens**

Unfortunately at present, there is no known cure for CF; however treatments are available and new research is ongoing to identify more effective treatments. In order to understand the barriers associated with compliance of CF treatment regimens, one must understand the various self-management interventions and treatments of CF. There are multiple treatments available to prevent respiratory complications in individuals with CF (Martiniano, Hoppe, Sagel, & Zemanick, 2014, p. 231).

Chest physical therapy (CPT) also known as percussion is commonly used to enhance breathing and to clear airway secretions. CPT involves pounding or percussing on the chest and back over and over with hands or with a distinct device in an attempt to loosen mucus from the alveolar walls in the lungs, enabling the mucous to be expectorated. It is recommended that the patient sit or lie down on their stomach with their head down to increase the use of gravity and force to help drain the mucus from the lungs. Devices have been developed to assist with CPT, for example, the electric chest clapper. The electric chest clapper is an inflatable therapy vest that uses high-frequency airwaves to force mucus deep in lungs toward upper airways in order to be coughed up. Some individuals use small handheld masks that can help dislodge mucus from the airways using vibrations (NIH, 2013). Exercise, particularly aerobic exercise, is helpful with lung secretions because it causes the patient to breathe harder, which helps to loosen mucus in the airways (NIH, 2013). It is important to note that while exercising, patients with CF lose a lot of salt through their sweat. If an individual with CF chooses to partake in exercise, a high-salt
diet or salt supplements are recommended. Pulmonary Rehabilitation (PR) is also used in addition to medical therapy to promote the well-being of patients with CF. PR includes exercise training, nutrition counseling, education, energy-conserving techniques, breathing strategies, and psychological training (NIH, 2013).

The medication regimen for individuals with CF is quite extensive and requires around the clock daily attention. Recommended medications for CF patients include antibiotics to help prevent lung infections, anti-inflammatory medicines to reduce swelling, bronchodilators to open up the airways and thin mucus, and medications to help clear and break down mucus such as mucolytic agents (NIH, 2013). Depending on individual symptom control, some of these medications may be added or removed. Also included in the medication regimen of these individuals is the digestive enzymes that need to be taken prior to every meal as mentioned previously. It is important that these digestive enzymes be taken before meals in order to aid in digestion since their own digestive enzymes are not able to reach the intestines.

Common digestive problems associated with CF include bulky stools, a swollen abdomen, constipation, and pain. However, nutritional therapy has the ability to improve and prevent digestive complications. A well-balanced diet that is rich in calories, fat, and protein is recommended for patients with CF. Examples of recommended foods include, high-calorie shakes, fatty and starchy foods, supplements of vitamins A, D, E, and K (ADEK) to replace fat-soluble vitamins that the intestines are unable to absorb (NIH, 2013).

**Nutritional Deficit Pathophysiology**

Nutritional deficits occur in individuals with CF due to chronic imbalance between the individual’s energy needs in relation to dietary intake (Haller, Ledder, Lewindon, Couper, Gaskin, & Oliver, 2014). Anorexia is a common concern for individuals with CF and can occur
from micronutrient deficiencies, sodium depletion, reduced appetite caused by abdominal discomfort, pulmonary exacerbations, chronic inflammation, or constipation. Further dietary complications arise from inadequate pancreatic enzyme replacement therapy (PERT). Excessive malabsorption of protein and fat can be lost in fecal matter due to lack of adequate intraduodenal bile acid concentrations from biliary disease and mucosal dysfunction due to small bowel bacterial overgrowth (Haller et al., 2014).

**Dietary Recommendations and Guidelines For Individuals with Cystic Fibrosis**

CF is a condition in which there is no overall consensus of international recommendations regarding anthropometric indications and benchmarks, estimation of energy needs, or supplementation regimens (Haller et al., 2014). As a result, the ultimate nutritional management goal is to maintain age-appropriate weight gain and growth. When it comes to dietary guidelines for individuals with CF, it is important to remember that proper weight gain is proportional to satisfactory lung function, while also aiding in the process of fighting off dangerous infections. Early identification of individuals who are at risk for nutritional failure is paramount and is of great importance when examining a patient during a nutritional assessment.

Chest infections are common in patients with CF and expend a significant amount of energy thus increasing energy demands, which is why it is important for these individuals to maintain high-energy diets. High-energy diets are essentially high protein diets that include a large portion of meat, fish, chicken, eggs and legumes. Although it is difficult for some individuals to eat a lot, it should be emphasized that they attempt to eat small and frequent meals. Consumption of high-calorie foods can help replenish energy stores and therefore aid in combating infections. It is known that individuals with CF often require 20-50% more calories each day than individuals without CF. Although consuming more calories a day does not seem
difficult, individuals with CF often experience a reduced appetite making it a challenge to keep up with these high-calorie requirements. Furthermore, keeping track of the number of digestive enzymes consumed before each meal is crucial to facilitate fat absorption. Improper consumption of enzymes can lead to a loss of fat and energy in stools leading to weight loss.

Dietary changes for individuals with CF must become a part of their everyday lives in order to be the most effective. For example, in order to increase consumption of fatty foods, individuals should choose unsaturated fats and oils because they are healthier and give the same amount of calories. Additional ways to increase the number of calories consumed during a meal is to encourage individuals to drink whole milk during every meal. Meal tips and tricks are crucial to satisfactory patient outcomes in regards to this specified diet, some examples would be adding cream to milk or cereal as a way to introduce even more calories to the diet. Additionally, parents can increase their child’s calorie intake by using whole milk dairy products whenever possible. It is extremely important for individuals with CF to consume high calorie foods and fat ultimately serves as the best source of calories. To put this into perspective, each teaspoon of fat has 45 calories, while protein and carbohydrates have 20 calories (CFChef).

Plasma fatty acids are usually low in individuals with CF due to malabsorption of fat. It is important that these individuals consume plant based oils that are rich in plasma fatty acids such as soybean oil. These oils facilitate rebuilding the cell membrane of epithelial cells, which help in the normal functioning of the lungs (Gowda, 2013). Omega 3 fatty acids are also crucial in this process. In order to incorporate omega 3 fatty acids in the diet, individuals with CF should consume foods such as flax seeds, salmon, and walnuts. As previously mentioned fats are not properly digested or absorbed in individuals with CF leading to low levels of fat-soluble vitamins. A deficiency in fat-soluble vitamins has an adverse effect on the immune system, which is why it
is important for individuals with CF to incorporate dietary supplements that are rich in vitamins A, D, E, and K. CF puts patients at risk for a variety of conditions, one of which is osteoporosis. Osteoporosis occurs from inadequate absorption of calcium from the diet. In order to prevent the occurrence of osteoporosis, it is important for individuals with CF to consume dairy products that are high in calcium and fat. Another chronic condition individuals with CF are at risk for is Anemia due to iron deficiency. Anemia is a condition that allows these individuals to become fatigued easily leading them to have poor resistance to infections. In order to combat iron deficiencies and supplement the lack of iron in the body, it is important for diets to include fortified cereal, dried fruit, green vegetables and meat. Individuals with CF may experience low blood pressure, high heart rate, dehydration, and heat strokes cause by loss of excess salt from the body through sweat. In order to prevent a patient from experiencing these symptoms, it is important to emphasize the importance of consuming salty foods on a daily basis to compensate for the loss of salt. Eggs, meat, liver, and seafood are important for patients with CF because these foods contain high levels of zinc. Zinc is instrumental in fighting infections, helps with growth, and aids the body in healing.

Recent studies from the Australian CF data registry conclude that children, two to five years of age were nourished according to their BMI’s, meaning that their BMI’s were in the normal range, while older children had BMI’s below the normal level indicative of malnourishment. There is a need for further research to determine why younger children appear to have better dietary compliance indicated by their BMIs when compared to older kids. Further studies have been conducted on the adult population and found that there is a gender disadvantage for females. According to the registry, approximately 25-30% of females were found to be underweight compared to 15-17% of males (Haller et al., 2014).
Barriers to Compliance

Unfortunately, CF treatment regimens are a life-long process requiring a significant amount of time and effort on a daily basis. Treatment regimens for CF are not only a demanding, but very complex. Between removal of mucus from the airways and self-administering medications it has been said that more than two hours is required for treatments each day (Sawicki, Sellers, & Robinson, 2009). However, compliance is crucial for patients with CF and the most important intervention that can be encouraged by health professionals. “Rates of adherence for children with CF are estimated to be 40-47% for chest physical therapy, a form of airway clearance, whereas adherence to dietary recommendations is even lower, ranging from 16 to 20%” (Modi & Quittner, 2006, P. 125). Although adherence has been proven to be lower when it comes to dietary restrictions; research has shown that following dietary restrictions properly and maintaining healthy eating habits is an important predictor of life expectancy in individuals with CF (Yen, Quinton, & Borowitz, 2013, p. 530).

According to Modi and Quittner (2006), both children and parents lack knowledge about nutrition such as the importance of offering snacks, taking enzymes before snacks/meals, and boosting calories. It is important to ensure that parents are adequately educated on the importance of proper nutrition so that they are able to instill healthy eating behaviors in their children and foster independence so they are able to properly manage their diet as they get older. A study by Filigno, Brannon, Chamerlain, Sullivan, Barnett, and Powers (2012) performed on families using a qualitative approach was aimed at understanding families’ experiences using behavior-nutrition intervention strategies and to identify challenges with CF management experienced by families during the developmental transition between toddlerhood and early school-age. Findings indicate that the biggest challenges in transition include picky eating,
parental stress, and transfer of treatment responsibility. Although mealtime behavior challenges are common and developmentally appropriate, they lead to low-caloric intake, which as mentioned above, is problematic for individuals with CF.

Parental stress was a major challenge in that parents felt a sense of desperation while trying to prepare meals that their children would agree to eat (Filigno et al., 2012). In addition, the transfer of treatment responsibility was particularly difficult for parents. One parent reported on their child, “She doesn’t get them [enzymes] for herself and she’s almost nine. We have to make sure she gets her enzymes when she gets in the snack drawer; she does not make any change in her behaviors herself (Filigno et al., 2012, p. 128).” This particular instance shows the struggle of transition between the parent caring for the child and the child learning how to independently and properly care for herself.

Although often overlooked, dietary compliance is vital to the well being of individuals with CF and has been linked to greater life expectancy. An observational study using data from the Cystic Fibrosis Foundation Registry (US) evaluated the relationship between nutritional status early in life and timing of height growth, lung function, complications of CF, and survival (Yen, Quinton, & Borowitz, 2013, p. 530). The findings of this study indicated that greater weight gain at the age of four years old was associated with greater height, better pulmonary function, fewer complications and better survival through 18 years (Yen, Quinton, & Borowitz, 2013, p. 533). Health lifestyles can be promoted by encouraging healthy eating habits early in children with CF.

**Psychological Barriers**

Individuals with CF frequently face depression and anxiety. In any chronic condition, symptoms of anxiety and depression have consequences including decreased compliance rates
and increased morbidity. Research has shown that there have been higher rates of depression in children, adolescents, and adults with CF. The evidence has shown that depression has negative effects on treatment adherence, family functioning, and health-related quality of life (Quittner, Barker, Snell, Grimley, Marciel, & Cruz, 2008, p. 582). In order to relieve anxiety and depressive symptoms, it is important to avoid adding additional medications to the child's pharmacology regimen unless absolutely necessary.

Interestingly, unlike other individuals with chronic conditions; those with CF cannot interact with their peers who also have CF. This is because children with CF often carry their own bacteria that does not harm them, but could be very dangerous if other children with CF contract the bacteria. This is problematic in that children with CF are unable to empathize directly with their peers, which has been said to be therapeutic by these patients. A peer-led asthma self-management program for adolescents was designed and later compared to an adult-led self-management group (Rhee, McQuillan, & Belyea, 2012). The findings indicate that the peer-led program was successful. Peer leaders appeared to have a positive effect as asthma outcome improved as a result of the program. Furthermore, peers reported a more positive experience with the peer-led group than the adult group. The findings further indicated that the participants of the peer-led group rated peer leaders highly on knowledge, attitudes, personal skills, and perceived similarities.

**Issues Experienced During Transitional Care**

Historically, the diagnosis of CF served as a death sentence for infants. When Dorothy Andersen first discovered CF in 1938, the majority of patients died shortly after the diagnosis (Cohen-Cymberknob, Shoseyov, & Kerem, 2011). Individuals diagnosed with CF in the 1980's had a median life expectancy less than 20 years. Fortunately, individuals with CF are living
longer than ever before and life expectancy has been improving steadily. Median survival age for the United States was approximately 37.5 years in 2010 (Burgel, Bellis, Olesen, et al., 2015). Prognosis is dependent on genotype, which predicts pancreatic function. According to Cohen-Cymberknoh, Shoseyok, and Kerem (2011), the most successful CF treatments that have led to improved pulmonary function and reduced exacerbations are treatments that target respiratory infections, inflammation, mucociliary clearance, and nutritional status. Furthermore, it is supported that treatment at a specialized CF center by a multidisciplinary dedicated team, including frequent visits, and periodic routine tests are essential to detect and treat early changes. However the concern, is that a large influx of adult-aged CF patients is something hospitals have yet to see and must be prepared for. According to Burgel, Bellis, Olesen, Viviani, Zolin, Blasi, & Elborn (2015) a study performed in 34 European countries, the number of patients living into adulthood is expected to increase tremendously within the next decade. It has also been found that as individuals with CF age, their disease process have more serious health concerns. For example, approximately 40-50% of all CF patients went on to develop diabetes (Burgel, Bellis, Olesen, et al., 2015). The complexity of the CF disease has been steadily rising as these individuals age, particularly because we have not had much experience with the disease process in older individuals.

As individuals with CF are living longer, it is crucial to explore their experience during the transition from pediatric care units to adult care units. One study was performed to explore how adolescents and young adults with chronic diseases experience the transition from pediatric to adult hospital care (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2013). The study concluded that four major barriers were identified including: facing changes in significant relationships, moving from a familiar culture to an unknown culture, being prepared for transfer,
and the achievement of responsibility (Fegran et al., 2013).

**Facing Changes In Significant Relationships & Transitional Care**

Individuals with chronic conditions reported that their relationships with healthcare professionals in the pediatric setting started early in their life and were transformative relationships in that they resulted into something more than just a professional caretaker relationship. For some individuals, the pediatric unit developed into a second home and nurses became like family members to them. According to Fegran et al. (2013), one individual stated, “The nurses had more time to spend with you... just spending that real quality time with you and just treating you like you were a real person” (As cited in Brumfield & Lansbury, 2004, p. 227). After transitioning from the pediatric unit, individuals described their relationships in adult care as very different from their relationships while in pediatric care. Some individuals reported that the doctors and nurses were described as being impersonal and particularly focused on disease. Due to the impersonal nature, individuals made statements about have a difficult time establishing relationships with their health care team during their transition. According to Fegran et al. (2013), One individual said, “I always felt the doctor's time is valuable and I’m always wasting their time as well, so I always try and rush through” (As cited in Jones et al., 2003, p.347). It is highly likely that if an individual feels as if they are unimportant than they may be less likely to comply with necessary treatments. Also, patients who feel rushed may feel uncomfortable asking questions leading them to be noncompliant with treatments and medications.

**Moving From Familiar to an Unknown Culture during Transitional Care**

The transition from pediatric care to adult care is essentially moving from a familiar health care environment to an unknown health care environment. During the transition, it’s
extremely important to note how well individuals are able to adapt to their new environments and the barriers that make adaptation more challenging. Pediatric units often take on the role of making the individual feel like they are at home with a focus on patient comfort. Games are found on the unit and the walls are decorated vibrantly. Additionally, child life specialists, play therapists and volunteers offer entertainment to provide distraction to pediatric patients. In contrast, the adult unit is very different in that the walls are bland and the rooms in general are not made to entertain the patients, rather individuals are expected to be mature and find ways to entertain themselves. According to Fegran et al. (2013), during the transition from pediatric care to adult care there is an indication of changed patient status. In the pediatric unit, health professional collaborate with parents in attempt to come up with solutions for health complications however, in the adult care units young adults are expected to deal with questions and decisions concerning their long-term health effects independently. According to Fegran et al. (2013), one individual stated:

At the paediatric centre they’d talk to the parents and say, you must make sure your child takes medication. At the adult centre, they tell you the benefits of it, they tell you what happens if you don’t take it, and leave it in your hands so, they give you a lot of control … they do talk to you like you’re an adult, it is your decision (As cited in Kirk, 2008, p. 570).

The transition experience requires young adults to take control of their care and show a sense of responsibility; something that has not been asked of them previously. In addition, on adult care units, young adults are expected to initiate follow-up appointments themselves. Some individuals stated they were prepared to take responsibility for their own care and found the new freedom beneficial, whereas others were in for a rude awakening.
Being Prepared for Transfer in Transitional care

The criteria for the transfer of care vastly differs across the board. Some institutions found that by the age of 16 the transfer should be initiated. However, some studies concluded that the time of transfer should be decided in consideration with age and readiness (Fegran et al., 2013). A lot of debate with regard to age and readiness has been discussed. According to Fegran et al. (2013) age should not be the sole consideration because you can have an 16 year-old individual ready for transfer and contrastingly have a 20 year-old individual who is not ready for transfer; rather it should be when the young person decides that they are ready for transfer (As cited in Soanes & Timmons, 2004). Some individuals stated that they knew they were ready for the transfer when they began to feel disconnected with the pediatric unit. Fegran et al. (2013) stated, one individual found that he knew when he was ready for the transition: “I changed at the time when I was about mid-teens... and that’s when I thought, thank god I’m going to a different clinic where it is not as noisy with all the kids running around... you feel out of place (Cited in Brumfield & Lansbury, 2004, p. 228). Advantages of transition to the adult care unit include being treated as an adult. According to Fegran et al. (2013), also state that some individuals found that pediatricians did not acknowledge that they were becoming adults and were able to comply with the medication regimens, however even still the pediatricians would continue to treat them as if they were ten years old and lecture them on the important of medication compliance (Cited in Brumfield & Lansbury, 2004, p. 228).

Sudden transfers were found to be the most problematic. Lack of preparedness caused many of these individuals to feel unwanted. Some individuals reported feeling “abandoned, dumped, or shuffled around” (Fegran, et al., 2013). Furthermore, young adults often experiencing other transitions aside from their medical care at this stage of their life. Many
young adults are graduating from school and transitioning to college and/or in some cases moving out of the home. Fegran et al. (2013) found that experiencing life transitions on top of medical care transitioning resulted in individuals feeling overwhelmed, and as if things were piling up on them (As cited in Soanes & Timmons, 2004).

An important consideration when discussing the transition from pediatric care to adult care is the collaboration between two hospital settings. It was found that during that transition, continuity of care was not always existent. According to Fegran et al. (2013), individuals experienced a sense of worry because often times adult-care providers may have little knowledge about a transferred patient's condition leading them to believe that they were not receiving the best care possible (As cited in Tuchman et al., 2008). Additionally, individuals found recounting their medical history to be tedious and tiresome.

**Achieving Responsibility**

Achieving responsibility essentially refers to the individuals taking ownership of their disease process after being transferred. Fegran et al. (2013) found that achieving responsibility was experienced different by individuals based on their own attitudes, severity, and time onset of their disorder, as well as parents' and doctors' incentives. Individuals expressed concern when feeling “thrown into being an adult” (As cited in McCurdy et al., 2006, P. 313). Fegran et al. discovered reluctant individuals were usually still dependent on their parents because they lived with their parents and the majority of the time the parent was still caring for the child (As cited in Moons et al., 2009). It is of great importance to have parental support when preparing children for this independence. Some ways parents are able to be supportive yet allow their child independence was to ask the young adult whether or not they the child desired the parents' presence during consultations. In some instances, it has been found that parents are reluctant to
let go of their responsibility and let their young adult take over (As cited in Kirk, 2008).

According to Fegran et al. (2013), one young adult stated, “My mom doesn’t want to let go. She has flat out told me. You put 18 years into your child’s health and it becomes your health as well” (As cited in Tuchman et al., 2008, p. 560).

Solution: Why Smartphone Apps?

It is apparent that the CF community would benefit from a solution focused on increasing compliance with treatment and dietary regiments, social support and interacting with peers, facilitation during transition from pediatric units to adult units including achieving responsibility for one’s own care and being prepared for transfer. Smartphones are mobile phone devices that have highly advanced capabilities to perform many of the same functions as a computer. For example, smartphones usually have Internet access and MP3 playing ability. Additionally, smartphones contain operating systems that are able to download a variety of apps. Over the last decade, there have been an increasing number of smartphone users. In 2015, there were approximately 182.6 million Americans using smartphones. According to Pew Research Center (2012), about one in four teenagers say that they own a smartphone. Furthermore, the growth of the smartphone market has been concentrated in young adults, primarily in the United States. Approximately 79% of young adults ages 18-24 own and use a smartphone (Smith, 2013). When considering these statistics, it is important to note that young adults are a high-risk population for CF complications due to non-compliance regarding poor dietary choices. Furthermore, these individuals are experiencing transition overwhelming transition periods. As a result, it is important to establish interventions in attempt to reach this population. With Smartphones becoming increasingly popular among this age group, they could be used as a solution to address the problem of decreased compliance as well as help facilitate in the transitional care process,
and serve as a platform for socializing with peers in the CF community. Health related smartphone apps have already been shown to be popular among smartphone users. According to recent research, 500 million users will use health apps by 2016 and sales are predicted to reach $1.5 billion (Jahns, 2010). The research supports the medical community embracing the use of smartphone apps.

Smartphones are used daily by teenagers. Parents have expressed how difficult it is to get their children to take initiative in caring for themselves independently, thus preparing them for transitional care. Smartphone apps have the capability to facilitate self-management of chronic conditions for individuals with CF and prepare them for transfer to adult units. By allowing children to monitor their own diets starting at a young age, they are more likely to maintain healthy eating behaviors later on in life. Furthermore, by instilling independent self-management behaviors in thesis individuals they are more likely to experience a more positive transition to adult units.

What Does those with Cystic Fibrosis Say About Smartphone Apps to Promote Adherence?

A recent study by Hilliard, Hahn, Ridge, Eakin, and Riekert (2014) was performed using individuals with CF’s input for the development of an adherence promotion app that would meet their preference and self-managing needs. This research indicated that the majority of health apps were diet-related but not conducive for CF management and stated that individuals with CF wanted a multi-purpose smartphone app rather than a single-purpose smartphone app. For example, one app might provide dietary education while another app would use alarms as reminders to take medications, however to find an app that would include both of these functions was rare. This specific study performed by Hilliard, Hahn, Ridge, Eakin, and Riekert (2014)
showed a desire to increase socialization within the CF community as well as enhancing communication with the healthcare team. One participant with CF stated:

...the chronic illness community as a whole is kind of lacking apps geared toward them because we live a completely different lifestyle than someone who is not...chronically ill... who doesn’t have the [same] kind of daily medical struggle or regimen (Hilliard et al., 2014, p.4).

Most diet apps are geared toward weight loss while the diets of individuals with CF are more focused on high calorie, fat and sodium intake (Hilliard et al., 2014). The same participant with CF from above shared her opinion on dietary smartphone apps, she stated: “I found that most of those are geared towards losing weight and I wanted to be gaining weight and...it wouldn’t...let me input a higher goal weight for me...I find that a lot of...health-related apps are generally limited to the general public” (Hilliard et al., 2014, p.4).

Individuals with CF experience a unique challenge in terms of wanting to gain weight. While there are a large number of smartphone apps focused on diets and nutrition the apps are primarily focused on weight loss. Very rarely do we encounter smartphone apps that have a primary focus on healthy weight gain. It is important for individuals with CF to feel supported in their journey and dietary challenges.

**Smartphone Apps Currently In Use**

In attempt to create a smartphone app that is both beneficial and accepted by the CF population, smartphone apps that are currently being used to manage various chronic conditions need to be evaluated. It is crucial to be aware of apps that are currently in use including what they offer, and how effective they are in managing chronic conditions. Furthermore, knowing which functions are available on these applications and how easy they are to navigate.
A recent study implemented a novel mHealth System to support complex self-care tasks, continuous adherence to regimens, monitor adherence, and secure two-way communication between patients and clinicians (Parmanto, Premana, Yu, Fairman, Dicianno, & McCue, 2013). The results of this study indicate that of the total app features, nine were considered to be relevant. Self-care tasks included in this particular app were: skin care, medication, bladder self-catheterization, bowel management, and mental health. The system was highly used on a consistent basis by patients. Furthermore, the findings of this study indicate that this smartphone app was successful at supporting self-care and adherence to regimen, monitoring adherence, and supporting the clinician-patient relationship.

According to Huckvale, Car, Morrison, & Car it was determined that of 103 apps for asthma, 56 of them were solely information about the condition, while 47 provided tools for the management of asthma (Huckvale, Car, Morrison, & Car, 2012). Interesting enough, none of the apps included both, information about asthma and management tools for asthma. Furthermore, many recommendations for proper control of asthma were unsupported by current evidence.

While looking into this study, it is apparent that smartphone apps for self-management although on the rise, still have a considerable amount of work to be done before they are considered useful by patients with chronic conditions. This particular instance supports that the utilization of the app relies heavily on the smartphones’ app features. Thus the more functions a smartphone app has, the more likely it will be utilized and hopefully prove beneficial.

There are currently some smartphone apps available for those affected with CF. One smartphone app that has been successful among the CF population is “My CF.” This app allows individuals the ability to email their medication list and sputum results, set 24 hour reminders for upcoming clinical appointments, and allows safe keeping for emergency numbers. A study was
conducted regarding this smartphone app and participants of the study confirmed the app was easy to navigate without instructions (Kaufman, Ratjen, & Al-Saleh, 2014). 32 participants consented to the app, however eight of the participants did not install the app and one participant chose not to participate in the study. Of the 23 participants, 65% of them reported using the smartphone app at least once a week. 87% reported that they enjoyed the smartphone app. All participants agreed that the app helped them to keep track of their medications, symptoms, and test results.

Another smartphone app that is unique when compared to the majority of other apps is an app created by Jerry Cahill, a 52-year-old male with CF. This smartphone app is called Jerry Cahill’s Cystic Fibrosis Podcast and essentially discusses Jerry’s views on living with CF and how he has been able to maintain a healthy lifestyle while living with the disease. This particular app contains features such as streaming access to play an episode from anywhere, updates with latest episodes, episodes can be downloaded and played when offline, and a favorite option to mark episodes to return to them at a later date. This smartphone app would be particularly attractive to individuals with CF because often, individuals with CF want to see what their future could possibly be like and Jerry provides them hope that CF can be successfully controlled. In addition, Jerry can relate to these individuals whereas apps created by medical professionals may not directly relate and fall short of what this patient population really needs from this technology.

A smartphone app created to keep track of CF regimens is called TCPal CF Treatment Tracker. This is a free smartphone app that allows the patient to organize and track treatments. It also allows the individual to set reminders. The useful part of this smartphone app is that it allows information to be shared with the healthcare team by generating reports. Progress is also
tracked using this app by day, week, month, and year. Further tracking for calories, lung function, and exercise can also be done using this smartphone app.

Acystant is another free smartphone app that is geared towards the parents of children with Cystic Fibrosis and teaches them how to create high-calorie meals for their children with CF. Useful features of this app include the ability to calculate the number of calories the child needs per day while also providing a countdown for the child reaching their weight goal.

Cystic Fibrosis Connect is a free app for the online social network website cysticfibrosisconnect.com. This app allows users to discuss their experiences, ask questions, and add comments on the go. This app is particularly important for individuals’ psychological health. As previously mentioned, peer support is limited and individuals with CF are unable to visit each other due to the ability to pass deadly infections between each other. An app such as CF Connect allows individuals with CF to support each other in their battle against CF.

All of these smartphone apps mentioned are helpful for patients. However, individuals with CF have expressed the want and need for one smartphone app including all of the above features. It can take up a lot of time and space and can become extremely disorganized when receiving medication reminders from one app, communicating with peers on another, communicating and transferring information to the health care team in another, and finding recipes for better dietary adherence in an additional app.

**Spirometry via Smartphone Apps**

Spirometry is a crucial test used to determine how well the lungs are functioning. For this reason, spirometry is extremely important for patients with chronic respiratory conditions, such as CF. Spirometry serves as a way to facilitate management, evaluate intervention efficacy, and determine lung disease stages (VanDevanter, Pasta, Konstan, 2014). Although spirometry is of
great importance, is not always accessible for patients. Spirometry testing often requires patients to access the healthcare system, which may not be possible for a variety of reasons. Patients may not be able to access the healthcare system due to financial, transportation, or scheduling reasons. Appointments may be difficult to schedule in busy healthcare offices, especially now that insurance is universal in the United States. Furthermore, finding a proper time to take children out of school in order to get to appointments has been said to be difficult among parents. With spirometry being a crucial indicator of a worsening condition in those individuals with CF, it is imperative to have access to this type of testing. However, similar to the majority of medical technology, spirometry is expensive and a major barrier for patients when attempting to purchase a spirometer of their own for their home. According to Larson, Goel, Boriello, Heltshe, Rosenfeld, and Patel (2013) high-end clinical spirometers can cost approximately $5,000. Portable spirometers generally cost between $1,000-$4,000. However, SpiroSmart is a smartphone-based approach at a spirometer. SpiroSmart measures lung function via the phone’s built in microphone so no attachments or additional hardware is necessary. Furthermore, popularity of smartphones has led to more reasonable pricing. As a result, smartphones are much more obtainable than spirometers. SpiroSmart has been proven as effective at diagnosing the presence of lung ailments as evidence by a low median error of just 8.01%. Spirosmart has the potential to be beneficial for patients with CF because they will be able to catch respiratory distress at its earliest stage thus, leading to improved patient outcomes.

**Introduction to Cystix**

While considering barriers individuals with CF experience on a daily basis as well as input from the CF population as a whole, a theoretical smartphone app proposal is in the works. Cystix is a theoretical smartphone app and would serve as a multi-purpose smartphone app used
to promote positive adherence behaviors in individuals with CF as well as provide an effective means for communication between the individual, peers, and the healthcare team. Furthermore, Cystix would increase self-management through the use of medication alerts, dietary education, food-journaling, facilitating transitional periods, enhance communication between the healthcare team and individual, and promote psychological well being through the use of a chat system.

**Cystix Dietary Helping Hand**

Cystix dietary platform would contain four crucial components: dietary education, food journaling, visual breakdown of food groups, and recipe ebook. Dietary education for the CF population is not only essential but very complex. The education portion of Cystix would include the importance of maintaining a high-calorie, high-fat, high-sodium diet. Education would include the role of digestive enzymes and the complications that arise from not taking the correct number of enzymes. In addition, an education module on how to read food labels properly would be included promoting self-care independence while making meal selections. Furthermore, the education module would provide interactive activities for individuals on how to determine the proper number of enzymes to take before a meal based on protein and fat content. The goal would be to have individuals with CF recognize high-energy foods from low energy foods and promote independence when making meal choices and adhering to medication regimens.

Education is particularly important for the success of this app because in order for individuals to successfully maintain a healthy diet, they must be aware of role of certain food groups in their diet. Many of the dietary recommendations and dietary guidelines mentioned above would be included in the dietary education section of this app.

The food journaling portion of this app is interactive and unique. The app would allow the individual to scan the barcode of the food they plan to eat or the different components of food
involved in making their meal and these would be automatically added to their food log for the day. Once added to their food log the number of calories in the meal would show up, along with vitamins, carbohydrate, sugar, fat, and sodium content. For example, if an individual was making a grilled cheese sandwich they would be able to scan the barcode of the bread, cheese, and butter, select the amounts of each product that they used such as two tablespoons of butter, and a grand total of how many calories they consumed would be entered into their food journal. Cystix is unique in that it allows the individual to put in their current weight and their desired weight within a specific time frame (for instance, over a 3 month period) and will then calculate the individual’s daily calorie goal. The input of each meal will keep a running total and the individual will be alerted when they have reached their calorie count for the day. The unique part of Cystix food journal is that when inputting meals, the app will also calculate the number of pancreatic enzymes that should be taken prior to the meal based on the fat content of what the individual will be consuming. This is not only helpful for teenagers as they are transitioning to caring for themselves independently, but also for parents who are struggling to properly calculate their child’s enzyme intake. Enzyme administration can be frustrating because some foods do not require enzymes at all. Some examples of foods that do not require enzymes are fruits, juice, coffee, gum, etc. (Adde, Rodrigues, & Cardoso, 2004). The Cystix food journal is appealing to all learning styles; the total day’s fat content, caloric intake, protein intake, and vitamin levels is documented in pie chart format as meals are added to the journal. In using this app, parents and teenagers would be able to visually distinguish which vitamins they are deficient in and would overall gain a better sense of their health without the need to look up health information of the food they are consuming. The idea is that the more the parent and teen are using this app the more they will learn. They will be able to determine their most prominent vitamin deficiencies
and become aware of which foods they must consume more frequently in order to combat these deficiencies. The recipe Ebook comes into play when noting the individual’s deficiencies. The recipe Ebook would include an option for individuals with CF to type in what food groups they are deficient in and discover different recipes they can use in order to get the necessary nutrients.

As Cystix is meant to be an emerging social media app for individuals with CF, it will also include an option to add an individual’s very own recipes that can then be shared with the CF community. When an individual finds recipes that they enjoy they can be added to their favorites list in their recipe ebook.

An important function of Cystix Dietary Helping Hand is that it will track the progress of an individual over a matter of days, weeks, months, and years and can therefore identify problem areas within the individual’s diet. For example, if the individual is consistently under eating every Monday and Tuesday the individual will be able to note this pattern and further look into what they are doing on Mondays and Tuesdays and why their caloric intake is lower on these days. Perhaps Mondays and Tuesdays are busier days for the individual and they don’t pack suitable snacks that can last for the duration of their day. The main goal of Cystix is to aid individuals with CF to make positive dietary choices independently thus gaining self-independence for treatment regimens and to promote healthy eating behaviors through the use of an easy to navigate smartphone app.

**Cystix Medication Adherence Help**

For many individuals with CF, daily treatments are time-consuming and tiresome. Many teenagers are going through transitions periods at this point in their life where they are trying to fit in with their peers and often fail to adhere to their medication regimens. According to a survey of young patients with CF and their parents, the major barriers to treatment adherences were lack
of time, forgetfulness, and unwillingness to take medication in public (Bregnballe, Schiotz, Boisen, Pressler, & Thastum, 2011). Cystix medication adherence help can remind individuals who are forgetful take their medications through the use of medication reminders in the form of alarms. Furthermore, the app is similar to an alarm clock in that it contains a “snooze button.” The purpose of the snooze button is so that if the individual is with peers or in the middle of an activity, they have the option to press the snooze button and they will be reminded again in 15 minutes. The hope is that with medication reminders, compliance will increase because individuals will be less likely to forget to take their medications. There are smartphone apps currently available that function solely to remind individuals with chronic conditions to take their medications; however Cystix is unique in that it is a multi-functional app and all features are located within one app, as opposed to multiple smartphone apps. A study was performed using a randomized controlled trial of four SMS reminder interventions with 48 weeks of follow up (Pop-Eleches et al., 2011). The results indicated that 53% of participants receiving reminders achieved adherence of at least 90% during the 48 weeks of the study, while only 40% of participants in the control group achieved adherence. The results of this study suggest that medication reminders via smartphone apps serve as an important tool to achieve an optimal treatment response.

Cystix Chat

As previously mentioned, it is contraindicated for individuals with CF to come into contact with other individuals with CF. However individuals with CF have shown interest in a smartphone app that increases socialization within the CF community. Cystix Chat would create an opportunity for socialization within the CF community through the use of an instant messaging system. This social media app would allow each individual to upload one photo and a
short biography including where they are from and their interests. The chat would allow individuals to add or decline individuals from their friend lists and chat with them. The idea is that Cystix Chat would give individuals an opportunity to chat with individuals similar to themselves about barriers they’ve experienced, solutions to those barriers, and ultimately an opportunity to empathize with their peers.

Most importantly, Cystix will provide support necessary to keep up with compliance and allow individuals with CF to be acknowledged for their hard work and dedication to their treatment regimens. If the individual is doing well, such as controlling their symptoms, taking their meds, and following dietary guidelines then they will see a happy smiley face emoji. They can also choose to post this as a status update and share their success with their peers. Additionally, any friends on Cystix Chat will have the option to comment or “like” their friend’s status update indicating that they support their change in health status. Contrastingly, an individual with CF may not be doing well, such as being uncompliant with treatment regimens, not controlling their symptoms, and not following dietary guidelines. As a result, this individual will receive the sad face emoji indicating poor treatment compliance. This has the potential to be helpful for individuals with CF because they can show their friends that their compliance is poor and peers can reach out and comment about tips and tricks to control symptoms, follow dietary guidelines, and ultimately live with CF on a daily basis.

Cystix Reports, Trends, & Healthcare Team Communication

Cystix will have the ability to create reports including medication adherence and dietary adherence. In addition, any deficiencies experienced during a specific time period will be documented in report format. Documentation of how often the snooze button is utilized will also be included in reports. The reports are not sent automatically to the individual’s healthcare team,
but rather the individual must assume the responsibility for sharing their reports with their provider due to the regulatory nature of HIPAA. Using Cystix report system, communication will be enhanced between the healthcare team and the individual. Furthermore, the individual will be able to utilize the notes section of the app to document symptoms including date, time, duration, and characteristics of specific symptoms, as well as questions that they have for their healthcare provider. The notes section also has the ability to be sent out in email format to the provider. The “notes” section will allow the healthcare team to answer any questions and be aware of any symptoms the individual is experiencing. This is particularly important during transitional care because new adult providers will be able to access medication lists and trends, symptoms experienced, dietary deficiencies, and previous questions the individual has had, which will facilitate transitional experiences in individuals with CF.

**Transitional Care Benefits of Cystix**

Transitional care is particularly important to note in individuals with CF as life expectancy is increasing. When examining transitional care barriers experienced by individuals with chronic conditions it was found that individuals reported that their relationships with pediatric staff evolved into something more than just a professional relationship. Individuals found that when transitioning to adult care units, doctors were impersonal and primarily focused on disease itself. However, the “notes” feature of Cystix would allow the patient to share their personal story with their healthcare provider and allow the provider access to important medical history, which has the potential to enhance relationships between individuals and their providers. The Cystix Chat portion of the smartphone app would allow individuals the ability to discuss transitional experiences with individuals who have already gone through the transition from pediatric to adult units and allows these individuals to share ideas on how to make the transition
go smoother. Transitional barriers include moving from a familiar to unfamiliar care
environment, being prepared to transfer, and achieving responsibility of their condition.
Individuals with CF discussed feelings of concern when being expected to deal with questions
and decisions regarding long-term care, not feeling prepared to transition, and difficulty
achieving independent responsibility of their condition. However, Cystix would greatly impact
the transitional experience of these individuals by promoting self-adherence and preparing
individuals for transitions by promoting individuals to take control of their disease with the use
of Cystix dietary helping hand and Cystix Medication Adherence Help.

**What Is Cystix Missing?**

Although Cystix is a multifunctional smartphone app, there are some functions that
Cystix is missing. According to a study regarding user preference and design recommendation to
promote CF self-management (Hilliard et al., 2014) individuals with CF expressed desire for an
app that contained an automation aspect of disease management, such as pharmacy refills. As
mentioned, CF requires specialty medications and the process of obtaining these medications
can be time-consuming. Appropriate paperwork must be filled out in order for patients to receive
their medications and coordination between health care providers and pharmacies is vital to this
process. Individuals with CF expressed issues remembering when they needed to get
prescriptions refilled along with keeping track of how many doses of medications they have left.
A 31 year-old individual with CF states:

The biggest thing for me would be the ability to manage medications all in one place. If I
need to refill prescriptions, being able to potentially do it straight from my phone with the
ability to tie into wherever I get my medicine from so that when I do need to renew it or
refill it, it's the click of a button or scanning of a bar code in the phone...If I could have
one central location that had all of my prescriptions that dealt with cystic fibrosis in one spot and I could refill them from that spot, that would make life a lot easier (Hilliard et al., 2014).

Although Cystix does not have this function planned currently; it is a possibility that refills could be coordinated through Cystix. Although there are many smartphone apps out there currently to help with self-adherence of medication, the majority of the apps currently in use do not have all necessary features important for medication adherence. In a systematic review of mobile apps currently available to patients to support outpatient medication self-management, of 424 apps 2.8% of them had the ability to check for drug interactions. Interesting enough, 91% of the apps provided medication reminders, while nearly half of the apps helped patients to create a logy and applications are examined and the advantages they have in increasing self organize their regimens, however few apps, approximately 6.2% of the smartphone apps were used by patients to help organize their medication regimens (Bailey, Belter, Pandit, Capentar, Carlos, & Wolf, 2014).

According to a study by Bailey, Belter, Pandit, Capentar, Carlos, & Wolf (2014), participants performed to determine what would be beneficial for a smartphone application, emphasized the need for integration of care and coordination with the healthcare team. Although Cysix report feature facilitates communication with the healthcare team, Cystix does not have a comprehensive feature including all communication desired in an app by the CF population. According to a study regarding user preference and design recommendation to promote CF self-management (Hilliard et al., 2014), individuals with CF find it important that a smartphone app to have the functionality of being able to promote communication with the healthcare team, particularly these individuals wanted to have the ability to share their medical information with
other people such as their health care providers. There is a disconnect in communication between visits. The ultimate goal for individuals with CF is to be able to communicate with CF providers in between visits. A 23 year-old individual with CF states, “I’m not always in a place where I can call them, so if I can just shoot a text...that would be convenient...If they want me to do something out of the ordinary...I want to [ask], ‘How exactly did you want me to do this?’” (Hilliard et al., 2014, p.7). Although, individuals have expressed their desire for a smartphone app that promotes communication with their provider via text messaging, some concerns have been brought up. One concern is that this type of communication may not be as responsive as traditional telephone communication. Further arguments include the fact that individuals do not want to replace human contact with providers (Hilliard et al., 2014).

**Barriers of Using Smartphone Apps for Self-monitoring**

Although smartphone apps serve as a reasonable solution to increase adherence in the CF population, there are some barriers of smartphone apps that should be recognized. A recent study by Hebden, Cook, Van Der Ploeg, & Allman-Farinelli (2012) was aimed at developing a smartphone app aimed at modifying key lifestyle behavior changes associated with weight gain during young adulthood. This study by Hebden, Cook, Van Der Ploeg, & Allman-Farinelli concluded that the main barrier found while using the smartphone app was the slow speed of the app due to the reliance on Internet connection. If individuals with CF rely on this smartphone app for their daily care regimens and become dependent on the app for self-management, there could be dangerous consequences. Internet connection is not guaranteed in rural areas or other countries. Additionally, Internet connections within the household can go down at any time and take minutes or days to restore. It is important to emphasize that smartphone apps should be used in individuals who are educated on their disease process and can effectively take care of
themselves, but individuals should not be solely dependent on the smartphone app. Other considerations for smartphone apps are that individuals may begin to use Cystix and then go back to their old self-care ways. It is important that Cystix is used daily so that progress measures can be tracked accurately. If the individual is only using the smartphone app once or twice a week, it is next to impossible to track progress or lack thereof.

**Medical Smartphone App Concerns**

Medical smartphone apps are a new and emerging topic. For this reason, little is known about the dangers of smartphone apps. One of the concerns regarding medical smartphone apps are that they have not been created based on evidence-based practice or by health care professionals; as a result, the reliability and accuracy of smartphone apps have been questioned. One solution to this problem is to have medical apps peer-reviewed by clinical experts prior to release (Buijink, Visser, & Marshall, 2012). As an additional safeguard, it has been recommended that regulatory measures for smartphone apps be increased to promote patient safety. It has been found that the majority of medical apps lack author, manufacture, and distributor information. Furthermore, references are unavailable and out-of-date. Smartphone apps have failed to address whether or not they will be updated when new evidence arises. Two studies within the fields of dermatology and microbiology indicated that less than 35% of medical apps had medical expert involvement in their development. A recent pharmaceutical sponsored app designed to assess disease severity was recalled because it was giving inaccurate scores; significantly different than when using the official formula. Current assessments of smartphone apps include usability, design, and content control (Buijink, Visser, & Marshall, 2012).

Legislation by the Food and Drug administration (FDA) has submitted a proposal on how
to regulate medical apps. "The FDA states that an app can be considered a medical device when it is used as an accessory to a regulated medical device (Buijink, Visser, & Marshall, 2012, p. 2)"

Although regulatory mechanisms or smartphones are important for patient safety, it is also important that government authorities do not over-regulate medical apps so that they are able to maintain their open nature. When debating which community should be in charge of regulatory function, it was found that the healthcare community was most appropriate to be in charge. However, as a way for the public to be aware that an app has been regulated it is recommended that health authorities provide official certification marks.

**Ensuring Smartphone App Quality & Safety**

Some recommendations have been discussed to ensure that smartphone apps are of high quality and most important, safe for patients. One recommendation is that all medical apps should be evidence-based, externally peer reviewed by medical professionals, and provide up-to-date clinical information (Buijink, Visser, & Marshall, 2012). In order to ensure smartphone apps are peer-reviewed, it has been suggested that a system could be implemented that would allow patient organizations specific to that particular smartphone app, adopt and develop the smartphone app. Furthermore, app developers and app reviewers should use guidelines to ensure quality and validity. As a safeguard, app developers should register their apps within the international directory as well as apply to accrediting bodies and medical experts who have the ability to assess the effectiveness and safety of the app (Buijink, Visser, & Marshall, 2012).

**Nursing Implications**

The creation of Cystix could have profound implications on nursing. Not only will Cystix help to promote satisfactory patient outcomes, but will also allow the healthcare team, including nurses the ability to care for their patients in a more comprehensive way. Nurses being granted
access to their patient notes section in Cystix will allow nurses to be aware of which parts of the disease process the patient needs education on. Furthermore, by being able to educate patients on areas of deficiency, the nurse is promoting self-adherence in these patients. As a result, Cystix, will promote satisfactory patient outcomes, patients will experience less hospitalizations thus leading to more beds for critical patients who need them as well as reduced healthcare costs. An important consideration is the effect Cystix will have on the nursing community and the role Cystix will play to help in the transition from pediatric to adult care units. The ability of Cystix to facilitate a seamless transition helps not only pediatric nurses, but nurses caring for these patients as they move to adult units. It can be very difficult for nurses to care for patients who have hostility toward being on a particular unit versus patients who are satisfied with their healthcare team. Cystix will allow individuals with CF to connect with kids like them from all over the world. This will allow the CF population to support each other in a way that hasn’t been possible before, and will enhance the psychological well-being of individuals who take advantage of the opportunity. Last but not least, the Cystix smartphone apps will allow the healthcare team to track progress through the reports system. This could lead to further research in that some individuals may experience cyclic exacerbations or new triggers to exacerbations that health care specialists can investigate. Exacerbations tend to arise more commonly in teenagers and young adults (Goss & Burns, 2007). Fewer exacerbations is heavily linked to better lung function.

**Conclusion**

The CF community continues to face problems when it comes to self-management regimens. It has been found that a smartphone app inclusive of dietary recommendations and tracking, medication reminders, as well as a social media platform would benefit this community.
This population experiences a variety of barriers when transitioning from pediatric to adult care units and a smartphone app has the unique potential to make the transition smoother for these individuals.
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