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The Use of Social Media and the Impact of Support on the Well-Being of Adult Cystic Fibrosis Patients

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by

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Dedication

For my parents --- Because graduate school is not cheap.

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Abstract

Cystic fibrosis (CF) is the most common, life-limiting autosomal recessive disorder of Caucasians. CF is a chronic condition that requires daily treatment of symptoms, the stress of which can have mental health consequences. Due to the potential for cross contamination of bacterial infections, individuals with CF are discouraged from meeting in person and must find other venues to receive support. Social media provides the opportunity for individuals with CF to communicate and provide support. We hypothesized a positive correlation between the patients' health-related quality of life and the amount of time spent on CF-related social media sites. We expected to see a positive correlation between the amount of time these patients spend on CF-related social media sites and their perceived value of these sites for CF-related emotional support. A quantitative survey was posted on social media sites with the intention of identifying trends between the patient's use of social media and their emotional wellbeing. Data from 103 adult participants with CF were used for statistical analysis while additional qualitative data was collected through 15 telephone interviews. Ninety-seven percent of participants reported using social media sites on average less than two hours per week, including Facebook groups (96%), blogs (38%), and online support groups (37%). The majority of participants (85%) were actively posting on these sites. Qualitative data was coded and analyzed using grounded theory methods. Qualitative analysis identified five major themes: (1) choice of social media sites (2) feelings of isolation due to CF; (3) use of social media for medical information;

(4) emotional support using social media; and (5) negative experiences using social media. Results indicated that individuals with CF are actively using social media sites for support related to their CF and there is a positive emotional response to social media with increased use and interaction ($p < 0.001$). The most statistically significant influential factors of the use of social media and level of interaction on these sites are the patient's perceived treatment burden ($p = 0.001$) and physical symptoms related to CF requiring therapy, such as the amount of chest therapy ($p = 0.002$).

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List of Abbreviations

ACTs ..... Airway Clearance Techniques

B. Cepacia ..... *Burkholderia Cepacia*

BMI ..... Body Mass Index

CF ..... Cystic Fibrosis

CFQoL ..... Cystic Fibrosis Quality of Life

CFQ-R ..... Cystic Fibrosis Questionnaire Revised

CFRD ..... Cystic Fibrosis Related Diabetes

CFTR ..... Cystic Fibrosis Transmembrane Conductance Receptor

FEV_1 ..... Forced Expiratory Volume

GT ..... Gastrostomy Tube

HRQoL ..... Health Related Quality of Life

P. Aeruginosa ..... *Pseudomonas aeruginosa*

PEI ..... Pancreatic Exocrine Insufficiency

PERT ..... Pancreatic Enzyme Replacement Therapy

UGC ..... User Generated Content

Chapter 1: Background

1.1 Cystic Fibrosis

Cystic fibrosis (CF) is a common, inherited disease that is progressive and life threatening. CF is caused by a mutation in the *cystic fibrosis transmembrane conductance regulator* (*CFTR)* gene, located on chromosome 7q31.2. The *CFTR* gene encodes the CFTR protein, which normally functions as a chloride channel in epithelial membranes. Normal CFTR is a cAMP-regulated chloride channel that regulates other ion channels. CFTR maintains the hydration of secretions within airways and ducts through the transport of chloride and inhibition of sodium uptake (Nussbaum et. al., 2007). The loss of CFTR function prevents chloride reabsorption in the duct of the sweat gland, which leads to a reduction in the gradient that normally drives sodium movement across cell membranes. This can increase chloride and sodium concentrations in sweat. In the lungs, this can lead to a depletion of airway surface liquid which increases the ability for bacteria to colonize and damage healthy lung tissue (Nussbaum, McInnes, Willard, Hamosh, & Thompson, 2007). CF is an autosomal recessive condition, which means that individuals with CF must inherit one copy of a gene with a CF causing mutation from each parent in order to have the condition. One out of every 25 Caucasians of northern European ancestry is a carrier for a *CFTR* gene mutation and has a 50% risk to pass the gene onto his or her child with each pregnancy. The incidence of CF in the United States is approximately 1 in 3,500 births with an estimated 30,000 affected individuals in the United States ("2012 Annual Patient Report," 2013).

CF has a wide range of clinical variability and severity among patients. This is in part due to the patient's specific mutations, as well as other genetic factors and the patient's environment. CF is a multisystem disease affecting chloride channels in the respiratory system, exocrine pancreas, male genital tract, hepatobiliary system, and exocrine sweat glands. These mutated chloride channels cause a thick layer of mucus to develop within the lungs, which can lead to chronic lung infections and obstructive respiratory disease. The most common cause of morbidity and mortality in cystic fibrosis patients is due to pulmonary disease (Moskowitz, Chmiel, & Sternen, 2001). Patients are prone to lower respiratory infections and chronic endobronchial infection, which can progress to end-stage lung disease. Since there is no cure, patients that reach end-stage lung disease will need a lung transplant if they qualify. In 2012, more than 200 CF patients received a lung transplant ("2012 Annual Patient Report," 2013). In addition, the majority (95%) of male CF patients are infertile due to azoospermia, which can be caused by absent, atrophic, or fibrotic Wolffian ducts (Moskowitz et al., 2001). Congenital bilateral absence of the vas deferens may be the primary or only organ system affected in male patients with milder forms of CF.

Defective chloride channels in the pancreas can cause reduced volumes of pancreatic secretion with low levels of bicarbonate. This is called Pancreatic Exocrine Insuffiency (PEI) and is characterized by chronic diarrhea with undigested food present. Lack of pancreatic secretion and fluid causes retention of digestive proenzymes retained in the pancreatic ducts and tissue destruction as a result of prematurely activated enzymes (Ratjen & Döring, 2003). Pancreatic duct obstruction prevents the enzyme release in the duodenum, which causes poor digestion of fat, proteins and carbohydrates. Malnutrition

occurs due to inadequate food digestion and increased energy needs (dietary recommendations) that are rarely achieved by CF patients. Meconium ileus, obstruction of the terminal ileum by thick meconium, is the first signal of PEI, which affects 15% of babies with CF (Haack, Aragao, & Novaes, 2013). This can lead to symptomatic vitamin insufficiency of one or more vitamins in newborn infants, which needs to be treated with oral fat-soluble vitamins. Signs and symptoms of intestinal malabsorption are early onset and are often present at birth and during the first year of life. Individuals with severe CFTR mutations on both alleles typically develop PEI during the first years of life (Haack et al., 2013). Early diagnosis and the treatment of complications of the respiratory and gastrointestinal tract in CF can lead to an improvement in the survival rate of CF patients. Pancreatic enzyme replacement therapy (PERT) is currently used to manage PEI and associated malabsorption in 85-90% of the CF population (Culhane, George, Pearo, & Spoede, 2013). PERT consists of "enteric coated microspheres, which decreases enzyme deterioration by stomach acid and improve the effectiveness of enzyme release in the duodenum when pH exceeds 5" (Culhane et al., 2013).

Patients who are treated with PERT may still experience fat malabsorption, and may only have 85% to 90% of intestinal fat absorption compared to the non CF individuals with >95% fat absorption (Culhane et al., 2013). Individuals with more severe malnutrition will have a lower Body Mass Index (BMI). There are many factors that contribute to inadequate calorie intake and weight loss in patients with CF. Calorie losses can be experienced from malabsorption and increased energy expenditure from lung infections. The 1992 CF nutrition consensus report recommended starting gastrostomy tube (GT) feeding if a patient was below 85% of their ideal body weight and failed other

nutrition intervention (Ramsey, Farrell, & Pencharz, 1992). Night-time GT feedings for supplemental nutrition therapy typically provides about 50% to 75% of estimated energy needs. Although GT feedings help to improve nutritional status, there are risks involved (decreased lung function, and poor pulmonary status) (Ramsey et al., 1992).

Other complications due to CF include diabetes, liver disease, gastrointestinal problems, bone disease, joint problems, delayed puberty, and reduced female fertility. Cystic fibrosis related diabetes (CFRD) is one of the most common complications of the disease. In 2012, 19.7% of people of all ages in the Patient Registry had CFRD, and 33.8% of people ages 18 years and older had CFRD ("2012 Annual Patient Report," 2013). High-caloric dietary intake and vitamin supplements are often necessary to offset the poor gastrointestinal absorption of fats and nutrients. In order to enhance nutrition and growth, patients with CF are recommended to consume between 110% and 200% of the recommended dietary intakes for healthy individuals (Stallings, Stark, Robinson, Feranchak, & Quinton, 2008). Data from the CF Patient Registry show that 36.0% of people with CF over the age of 35 reported bone disease (e.g., fracture, osteopenia or osteoporosis) or joint problems ("2012 Annual Patient Report," 2013).

In 1969, CF patients in industrialized countries had a mean survival of 14 years (Doring, Flume, Heijerman, & Elborn, 2012). Currently, the median lifetime age expectancy of a CF patient in the United States is 41.1 years old ("2012 Annual Patient Report," 2013). In 1991, over 32% of CF patients in the United States were over 18 years old and in 2012, more than 49% of CF patients in the United States are over 18 years old ("2012 Annual Patient Report," 2013).

CF is a chronic condition that requires complex medical management for the patient's entire life. Current treatments are palliative rather than curative. Daily oral and inhaled medications are required in addition to airway clearance techniques (ACTs). ACTs are required multiple times per day to manually clear patient's lungs of thick mucus. It is important to clear the mucus, which can provide a surface for microbes to grow and if not cleared, may lead to lung infections, which causes lung damage. ACTs usually consist of chest physiotherapy: positioning for mucus drainage, active breathing techniques, and manual clearance techniques (Badlan, 2006).

Forced expiratory volume (FEV_1) is a measure of pulmonary function, which measures the forced exhaled volume in the first second of an exhaled breath ("2012 Annual Patient Report," 2013). Over time, individuals with CF have progressive lung damage from constant infections. By comparing a patient's FEV_1 measurements over time, the amount of a patient's lung damage can be monitored. There is a positive correlation between the FEV_1 measurement and amount of lung function, as the FEV_1 declines, lung function also declines. FEV_1 values are compared to a predicted value for an individual's age, gender, height, and weight. Greater than 90% predicted is considered normal lung function. 70-89% FEV_1 indicates mild lung disease, 40-69% FEV_1 indicates moderate lung disease, and a FEV_1 less than 40% indicates severe lung disease ("2012 Annual Patient Report," 2013).

Pulmonary disease in CF patients can be exacerbated by pulmonary viral, bacterial, and fungal infections. Individuals with CF are highly susceptible to bacterial infections in the respiratory tract. Intensive antibiotic therapies are required to maintain lung function and quality of life (Doring et al., 2012). These bacterial infections can enter

the lower airways and can persist, recur, or eventually develop into a chronic infection. Chronic infections can result in a progressive loss of lung function due to a prolonged inflammatory response (Doring et al., 2012). Antibiotic therapy aimed at eradicating the major bacterial pathogen in CF patients, *Pseudomonas aeruginosa* (*P. aeruginosa),* has played a major role in the increased median survival age of adult CF patients. Another highly damaging bacteria, *B. cepacia,* is a pan-antibiotic resistant strain of bacteria. While some antibiotic treatments have been helpful to avoid pulmonary decline, the most effective method of preventing lung damage from these life threatening infections is to avoid risk of infection altogether.

In order to reduce the amount of bacterial transmissions between CF patients, the Cystic Fibrosis Foundation released an Infection Prevention and Control policy in 2003 which was recently updated in 2013. These infection control guidelines aim to reduce the risk of cross infection between patients. The policy states:

> Only one person with CF may attend a foundation sponsored indoor event, patients must maintain a 6 foot distance from each other at outdoor events, and patients who have ever tested positive for *B. cepacia* may never attend a foundation sponsored event.

Individuals with CF should avoid the following activities with other individuals with CF: shaking hands, hugging or physical contact; kissing or intimate contact; riding in the same vehicle or sharing the same car; fitness/exercise class at the same time; and sharing personal items, drinking cups, utensils, or respiratory equipment (Saiman, 2003). CF patients and their families must be educated on ways to prevent transmission of respiratory pathogens. This policy discourages and prevents CF patients from attending

in-person support groups with other CF patients. As a result of the physical restrictions on direct in-person contact among groups of CF patients, unlike other chronic conditions such as sickle cell disease or diabetes, CF patients cannot receive typical, direct social support from other individuals affected by CF.

1.2. Adult CF Patient's Quality of Life

People with chronic illness live in "the dual kingdoms of the well and the sick" (Donnelly, 1993; Patterson, 2001). Patterson recently hypothesized: Patients have shifting perspectives on their illness, meaning persons with chronic illness sometimes have illness in their psychological foreground and sometimes wellness. This "Shifting Perspectives model" is due in part to the waxing and waning of the disease in addition to psychological factors. The severity of the individual's illness is not as important as how significant the individual actually perceives his or her disease to be. "The perception of reality, not the reality itself, is the essence of how people with chronic illness interpret and respond to their illness" (Patterson, 2001).

Depression is a significant risk factor for poor health outcomes among individuals with chronic illnesses. According to the 2012 Cystic Fibrosis Foundation Patient registry, 22.2% of adults with CF have signs of depression ("2012 Annual Patient Report," 2013). In individuals with a chronic disease, depression is associated with non-adherence to treatment. One study showed non-adherence to medication in patients increased by a factor of 1.76 as a result of depression (Mitchell, 2012). People with chronic health problems were more likely to be unemployed or work part time and were more likely to have significantly decreased ability to participate in day to day activities than individuals without chronic illness (Mitchell, 2012).

As more individuals with CF are surviving and living to adult ages and beyond, there has been a significant rise in the amount of research devoted to investigating the well-being of these adult CF patients. As CF patients age, the management of their condition can become more complicated. Two major life challenges emerge for adolescents with CF: managing their CF and maintaining a satisfactory life (Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009). It is important that adolescents with CF learn how to balance the limitations and demands of having CF with the developmental goals associated with transitioning to adulthood and becoming independent (Badlan, 2006; Gjengedal, Rustøen, Wahl, & Hanestad, 2003; Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009). Because the demands of CF typically begin to decrease in adolescence, this can be a particularly challenging period (Ernst, Johnson, & Stark, 2011). Daily treatments for adults with CF include the use of PERTs, monitoring of caloric intake, chest physiotherapy, inhaled bronchodilators, inhaled antibiotics, inhaled mucolytics, and anti-inflammatory therapies (Sawicki, Sellers, & Robinson, 2011). During exacerbations, patients are often hospitalized to receive intravenous antibiotics, have a portacath to receive medications, or have a GT to receive supplemental feedings. Adult CF patients are likely to experience many social norms, such as relationships, friendships, a career, and family. Individuals with CF hope for a normal life, desire long-term relationships, and/or marriage, children, and a good career (Higham, Ahmed, & Ahmed, 2013). CF patients can feel a sense of being an "imposter" in the normal world as they age due to increased CF-related symptoms and treatments (Badlan, 2006). Previous studies have found that disease management can become onerous over time, with young adults finding it increasingly difficult to fulfill their aspirations for a "normal" life as a result on

restrictions placed on them by its requirements. This tends to result in a "trade-off" between quality and quantity of life, which sees young people reducing the amount of self-care they are prepared to undertake (Badlan, 2006).

In addition, research shows that adults with CF can be socially maladjusted due to difficulties in developing interpersonal relationships (Pfeffer, Pfeffer, & Hodson, 2003). As these patients reach adulthood, they must cope with and accept their chronic illness. A defining characteristic of acceptance is to reject the idea that acceptance of illness is a sign of weakness, failure, helplessness, or inferiority (Risdon, Eccleston, Crombezc, & McCracken, 2003). Acceptance involves acknowledging the reality of being chronically ill, namely that a cure will most likely not be found, without resigning or surrendering. Worsening disease severity, along with challenges to daily self-management, may impact the health-related quality of life of adults with CF (Sawicki et al., 2011).

Health Related Quality of Life (HRQoL) is a "measurement that provides unique information about the impact of an illness and effectiveness of various treatments, in which the treatment aims to improve daily functioning and overall well-being" (Drotar, 1998). The HRQoL measurement for CF patients has been used through a validated questionnaire, the Cystic Fibrosis Quality of Life (CFQoL) questionnaire (A. L. Quittner et al., 2000). The CFQoL has been used in recent studies to examine emotional adjustment, illness perceptions, and anxiety and depression in adult CF individuals. A significant amount of variance in the HRQoL of CF patients can be attributed to treatment burden, coping style, and health perceptions (Staab et al., 1998). For example, Havermans et al. found that adult CF patients who reported symptoms of anxiety had poorer HRQoL scores for vitality, emotional functioning, social, treatment burden, health

perceptions and respiratory symptoms. Lower HRQoL scores for emotional functioning, eating disturbances and body image were reported in individuals with depressive symptoms (Havermans, Colpaert, & Dupont, 2008). A previous study using the Cystic Fibrosis Questionnaire-Revised (to evaluate mental health) and FEV_1 (to evaluate physical health) found depressive symptoms were common in adults with CF and individuals with depressive symptoms were more likely to have poorer health related quality of life (Riekert, Bartlett, Boyle, Krishnan, & Rand, 2007). For those CF patients who have been infected with the bacterial infection, *B. cepacia,* segregation from other patients caused feelings of isolation, anger, and, on occasion, feelings of being a "microbiological leper" (Duff, 2002).

Previous studies have shown that adolescent females with CF have been shown to have a higher mortality and poorer health-related quality of life than males (Arias Llorente, Bousono Garcia, & Diaz Martin, 2008). Declines in pulmonary function start earlier for girls and up to the age of 20 years, the relative chance of survival for females is lower compared to males. This difference in mortality and survival has been termed the "CF gender gap." The female sex hormone estrogen has been implicated as a factor that modulates components of CF lung physiology including airway infection, dysregulated inflammation and transepithelial ion and fluid transport (Sweezey & Ratjen, 2014). Estrogen has been suggested to aggravate CF airway tissue damage via lung inflammation. Several psychosocial factors are also believed to be related to this gender gap, including: decreased adherence to the high-fat diet and other aspects of treatment, suppression of coughing due to greater public self-consciousness seen in females, and limiting physical activity due to the inability to keep up with their peers (Patterson, Wall,

Berge, & Milla, 2009). Adolescent females also had greater strains in their relationships, namely their relationships with family members and peers, which illustrates that girls may be more attuned to how others perceive and respond to them and hence report greater strain when things are not going well.

A German study, which analyzed age-related differences in psychosocial development of adult CF patients, found that the differential age-related differences in life satisfaction indicate that independence from help/care, absence of pain, and successful integration of therapy into daily routine are crucial factors for patients, regardless of age (Besier & Goldbeck, 2012). Elevated symptoms of anxiety and/or depression (used as indicators of psychological well-being) had a strong negative association with life satisfaction. Most patients in this study with CF achieved ordinary social and vocational development into adulthood. The study concluded that a favorable mental health status seems more important than pulmonary function to maintain a good satisfaction with life (Besier & Goldbeck, 2012).

One qualitative study, which interviewed young adults with CF, addressed the lack of support groups for adults with cystic fibrosis, due to the possibility of cross infection (Badlan, 2006). Patients mentioned the sense of isolation due to the lack of access to support groups and the negative impact that this sense of isolation could have on their health care management. Research has shown that young adult participants feared the unpredictable nature of CF and the suffering that they believed they would have to endure due to ill health before their premature death, which suggests that young adults need psychosocial support (Higham et al., 2013).

D'Auria et al. (2000) found that repeated hospital visits provided adolescents with new friends who shared their same attributes and life experiences, which helped to develop a sense of identity and belonging. These friendships reinforced the downward progressive nature of CF and inspired patient adherence to treatment, a positive attitude, and hope (D'Auria, Christian, Henderson, & Haynes, 2000). Similarly, Abbott et al. (2008) found that HRQoL is significantly impacted by the patient's coping style and the two most common coping styles for adult CF patients are optimistic acceptance (cognitive approach) and distraction (behavior avoidance). Individuals who were optimistic about their CF and accepted their future with CF had superior quality of life (Abbott, Hart, Morton, Gee, & Conway, 2008). Patients may make themselves feel better by choosing to "forget" and "escape" their CF without confronting their disease (Abbott et al., 2008). This need for distraction may lead to an increase in risk-seeking behavior, such as smoking, drinking alcohol, and drugs (Suris & Parera, 2005; Withers, 2012). All of these risky behaviors can lead to further health complications, such as decreased lung function from smoking or pancreatitis from drinking alcohol.

1.3. Social Media

Since the advent of the Internet, online support groups have developed. A support group is defined as "a group of people, sometimes led by a professional, who provide each other with moral support, information and advice relating to a shared characteristic or experience" (Plumridge, Metcalfe, Coad, & Gill, 2012). Participants can share information and develop friendships, which can reduce users' feelings of isolation (Johnson, Ravert, & Everton, 2001). People can participate in online communities in two ways: Those who actively interact on these sites are known as posters, and individuals

who passively read these sites and do not publish messages are known as lurkers (Setoyama, Yamazaki, & Namayama, 2011). Lurkers do not help or provide others with advice in the online support groups (van Uden-Kraan, Drossaert, Taal, Seydel, & Vandelaar, 2009). Social networking sites illustrate the fusion of key elements of human desire—to express one's identity, to create community, to structure one's past and present experiences temporally—with the main technological features of 21st century digital communication (speed, reach, anonymity, interactivity, broad- band, wide user base) (Gurak & Antonijevic, 2008).

One type of online support method that has recently gained popularity and fits all of these requirements is social media. Any website that allows for social interaction is considered a social media site. Social media has gained popularity in the past decade: among Internet users, social networking use increased from 8% to 67% from 2005 to 2012 (O'Keeffe & Clarke-Pearson, 2011). In 2013, 73% of adults were found to now use a social networking site of some kind (Duggan & Smith, 2014). The adoption of social media in the mainstream has moved the Internet beyond a tool for obtaining health care information passively to an outlet to engage others in a very participatory manner, so called peer-to-peer health care. Social network sites are unique from solely text-based communication formats, in that relationship building can be enhanced by profile pages, friending, and unique messaging features (Wagner-Johnston, 2013).

Kaplan and Haenlein (2010) define social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content." Web 2.0 is described as a platform whereby content and applications are no longer created and published by

individuals, but instead are continuously modified by all users in a participatory and collaborative fashion. User Generated Content (UGC) is available on a publicly accessible website or on a social networking site accessible to a selected group of people, show a certain amount of creative effort and needs to have been created outside of professional routines and practices (Kaplan & Haenlein, 2010).

Social media comes in a variety of forms, with the main categories including blogs, collaborative projects, content communities, and social networking (Kaplan & Haenlein, 2010). Blogs represent the earliest form of social media. Blogs are generally defined as "web-based journals in which entries are published in reverse chronological sequence" and also contain a space for other users to comment on the journal entry (Rains & Keating, 2011). Collaborative projects, such as Wikipedia, are based on the idea that the joint effort of many actors leads to a better outcome than any actor could achieve individually and allow users to add, remove, and change text-based content (Kaplan & Haenlein, 2010). Content communities involve sharing of media content between users and usually do not require users to create a "profile" with more than their basic information. Current popular examples of content communities are Pinterest™, YouTube™, Vine™, and Instagram™.

Social networking sites are applications that enable users to connect by creating personal information profiles, inviting friends and colleagues to have access to those profiles, and sending e-mails and instant messages between each other (Kaplan & Haenlein, 2010). These social networking sites include, but are not limited to: Facebook™, Twitter™, and (previously) MySpace™. Facebook™'s mission is to give people the power to share and make the world more open and connected. Facebook™,

founded in 2004, allows individuals to create profiles and share information with friends including photos, links, and videos (Facebook, 2013). As of March 2013, there are 1.11 billion monthly active Facebook users (a 23% increase from 901 million in March 2012) and 665 million daily active users (a 26% increase from 526 million in March 2012) (Facebook, 2013). Currently, there are many groups related to cystic fibrosis on Facebook. Many of these groups are by invitation only and allow adults with CF to connect with each other via writing comments in the group or sharing photos and videos. Other group members can "like" a post or comment on the post in response. Twitter™ is a "microblogging" website in which individuals share "small bursts of information called Tweets," which up to 140 characters long (Twitter, 2013). Users can add a hashtag symbol (#) before a key phrase, which can be used to categorize their message with other users.

1.4. Social Media as a Form of Support

Research suggests that "health communication is more effective when it reaches people on an emotional as well as a rational level, relates to people's social or life contexts, is a combination of interpersonal communication and mass media, is tailored, and is interactive" (Shaw & Johnson, 2011). Social networks enable individuals to exchange information on such subjects such as bodily symptoms, clinical diagnosis and treatment options, adverse treatment effects, sources of medical evidence, experiences with individual providers and opinions about their quality (Griffiths et al., 2012). While support groups for genetic conditions offers the support of others who have similar experiences, a potential drawback is the user being confronted with a "vision of the future" (Plumridge et al., 2012).

Research has found that searching for healthcare information is the third most popular use of the Internet, with an estimated 89 million US adults using social networking sites for health-related purposes in 2010 (Broom, 2005; Thoren, Metze, Buhrer, & Garten, 2013). With instant and easy access, the Internet allows participants to access these support groups from their home and allows participants to retain their anonymity. Participants are able to communicate with other users around the world, unlike in person support groups, which usually consist of people from similar geographical areas and backgrounds. Online support groups are able to overcome many of the attendance barriers due to lack of access, especially for remote geographical locations, and are convenient, cost-effective, anonymous, and can be easily updated and provide links to other resources (Beatty & Lambert, 2013). Online social support programs targeting chronic illness have been shown to decrease symptoms and improve health behaviors, self-efficacy, and satisfaction with health service (Lorig et al., 2008). These support groups can foster a sense of community and increase the availability of social support. Previous studies found that users felt online support groups replaced the networks that their families and friends were not providing (Plumridge et al., 2012).

One recent study focused on patient empowerment that occurs as a result of use of online support groups for a chronic illness, such as breast cancer, fibromyalgia, and arthritis. The respondents mentioned the following empowering outcomes: being better informed, feeling confident with their physician, their treatment and their social environment, improved acceptance of the illness, increased optimism and control, enhanced self-esteem and social wellbeing and collective action (van Uden-Kraan et al., 2009). Almost half of the participants (47%) felt less lonely as a result of participation in

an online support group (van Uden-Kraan et al., 2009). Patients expressed they had better questions to ask their doctor and were better prepared for doctor appointments. Some individuals could clarify their needs better to a doctor due to online support groups.

Previous studies have found that while women are more likely to claim they use the Internet to seek social support, men are more likely to claim to use the Internet to seek information (Seale, Ziebland, & Charteris-Black, 2006). However, a study that focused on the use of online support groups for patients with prostate cancer indicated that accessing information and support online could have a profound effect on men's experiences of prostate cancer. These online support groups allowed men to have "a unique and liberating source of support and information, limiting inhibitions felt in face-to-face encounters, and allowing men to transcend cultural expectations of masculinity for men to express emotions and intimacy" (Broom, 2005). The idea of anonymity appealed to men, and they felt able to express experiences they typically would not feel comfortable sharing in a face-to-face encounter. Although web forums are considered a 'public' place to communicate with others, individuals subjectively experience them as 'private' locations, and are able to discuss intimate details of bodily experience more freely than in research interviews (Seale et al., 2006).

There have been multiple studies of social media usage involving patients with a chronic illness, mainly diabetes. One study found that a majority of their participants with diabetes seek online health information (Shaw & Johnson, 2011). A majority of the study participants used social media and were willing to discuss health related information via these venues. This study found that web-based venues could be beneficial in promoting health behavior change and serve as a setting to deliver and improve diabetes social

support. Many of the participants in this study use traditional social networking sites, such as Facebook™ or Myspace™. In addition, many of the participants used social networking sites devoted to diabetes, such as Diabetesfriends.net, with over 1,000 members, or Tudiabetes.org, with over 16,000 members (Shaw & Johnson, 2011). Similar websites are available for individuals affected with CF, such as CysticLife.org and CFLiving.com.

A content analysis by Torre-Diez et. al investigated the use of Facebook™ and Twitter™ by diabetes patients in addition to patients with colorectal cancer and patients with breast cancer. This analysis found that 18% of the studied online groups for all three diseases are dedicated to supporting patients and their relatives (De la Torre-Diez, Diaz-Pernas, & Anton-Rodriguez, 2012). Twenty three percent of diabetes related groups were found to be used for supporting patients and their relatives and to illustrate that ordinary life with the disease is possible (De la Torre-Diez et al., 2012). In this content analysis study, diabetes, which like CF is a chronic illness, had the highest amount of social media sites dedicated to support purposes.

Other forms of social media, such as health related blogs, are also available to support patients. Blogging about health-related issues is predicted to be positively associated with perceived social support from blog readers and individuals who blog more frequently and whose posts generate more reader responses should generally perceive more support from blog readers. Blogging frequency, mean words written per post, mean reader responses per post, and the total proportion of posts with a response should all be positively associated with perceived social support from blog readers (Rains & Keating, 2011). Rains and Keating found that reader feedback is an important

component of health blogging and reader support was positively associated with the blogger's perception of disease self-efficacy (Rains & Keating, 2011).

A previous study by a University of South Carolina genetic counseling student found that parents of children with trisomies (Trisomy 13, 18, or 21) felt that social media has allowed them to gather and share information, express their emotions openly and freely, and provided a sense of community in which they can connect with other families that have children with these conditions. Participants expressed that healthcare professionals should be providing social media as a support option. Parents commented that by providing this resource, genetic counselors and healthcare professionals will become more aware of social media use by these families and begin to feel comfortable providing and suggesting social media as a support option (Edwardsen, Sellers, Brasington, & Hook, 2013).

Currently, only one study has been published about the use of the Internet by individuals with CF. This Brazilian study was qualitative and interviews were focused around the guiding question, "Tell me about your experience with the Internet as a means of information and exchange of experiences about CF" (Pimentel, Luz, Pelloso, & Carvalho, 2013). According to the participants of this study (fifteen patients and seven family members), the most widely used Internet media were websites related to seeking information about CF. Three themes emerged about the experience of using the Internet as a means of information and communication. The first theme, "Scientific and technical aspects of virtual information about CF", emerged from patient use of the Internet to search for information about the disease CF. The second theme, "Emotional support through virtual relationships", provided participants with "the opportunity to share

questions and express intimate and personal feelings about the difficulties of living with CF." The final theme, "Modes of disseminating CF information:" in search of healing, found that participants suggested having prior knowledge about [CF] before any Internet consultation on CF in order to avoid reading websites with unreliable information . This study posited that the Internet may prove to be a medium of opinion formation that could eventually replace medical advice. This study concluded that it may be important to establish criteria for constructing and monitoring information related to CF published on Internet websites (Pimentel et al., 2013).

Along with the advantages to social media support groups, there are downfalls for social media users. Due to the open accessibility and ability for anyone to post on these large forums, misinformation can be perpetuated to others (Mo & Coulson, 2013). In addition, there is a possibility that individuals may misread or misunderstand text-based communication, especially individuals with intellectual disabilities (Shpigelman & Gill, 2014). These negative experiences may be due to "anonymity, lack of real-time responses, and lack of social status cues that normally inhibit inappropriate responses" (Braithwaite, Waldron, & Finn, 1999). This can lead to interactions within online support groups may becoming more disinhibited, which can increase the possibility of offensive or antisocial behavior (Lee, 1996). A 2008 study with 32 participants of online support groups for breast cancer, arthritis, or fibromyalgia found that the disempowering processes mentioned most commonly was "being unsure about the equality of the information, being confronted with the negative sides of the disease, and the presence of complainers" (van Uden-Kraan et al., 2009).

The Internet has the potential to empower patients and increase their control over their disease (Broom, 2005). The above referenced studies have found a positive correlation between patient use of various types of social media (i.e., Facebook™, Twitter™, health blogs, social networking sites) and the patients' enhanced assessment of the treatment options recommended by their health care providers. Patients with either chronic diseases, such as diabetes and arthritis, or other life threatening diseases, such as breast or colorectal cancer, use online support groups and social media for emotional support to cope with their disease. These sites promote feelings of empowerment and positive feelings of disease self-efficacy, which may be beneficial to overall patient well-being and coping throughout the patient's treatment (for life threatening diseases) and which may extend throughout the patient's lifespan (for chronic diseases).

To date, current literature is lacking research that examines adult CF patients' utility of online support groups and social media. The primary objectives of this study include determining the amount of time participants utilize social media for social and emotional support, the participant's motivation for seeking support, the level of support participants received during their use of social media, and the social media sites the participant used for CF-related support. Another objective of this study is to assess the participant's mental and physical health, related to their use of social media as a support system. We hypothesize that there is a positive correlation between the patients' health related quality of life and the amount of time spent on CF-related social media sites. There is also expected to be a positive correlation between the amount of time these patients spend on CF-related social media sites and their perceived value of these sites for CF-related emotional support.

Chapter 2: The Use of Social Media and the Impact of Support on the Well-being of Adult Cystic Fibrosis Patients[1]

2.1 Abstract

Cystic fibrosis (CF) is the most common, life-limiting autosomal recessive disorder of Caucasians. CF is a chronic condition that requires daily treatment of symptoms, the stress of which can have mental health consequences. Due to the potential for cross contamination of bacterial infections, individuals with CF are discouraged from meeting in person and must find other venues to receive support. Social media provides the opportunity for individuals with CF to communicate and provide support. We hypothesized a positive correlation between the patients' health-related quality of life and the amount of time spent on CF-related social media sites. We expected to see a positive correlation between the amount of time these patients spend on CF-related social media sites and their perceived value of these sites for CF-related emotional support. A quantitative survey was posted on social media sites with the intention of identifying trends between the patient's use of social media and their emotional wellbeing. Data from 103 adult participants with CF were used for statistical analysis while additional qualitative data was collected through 15 telephone interviews. Ninety-seven percent of participants reported using social media sites on average less than two hours per week, including Facebook groups (96%), blogs (38%), and online support groups (37%). The majority of participants (85%) were actively posting on these

[1] Faust, M., Sellers, A., Weinke, S., Eshbaugh, A., & Rainwater, A. To be submitted to *Journal of Cystic Fibrosis*

sites. Qualitative data was coded and analyzed using grounded theory methods. Qualitative analysis identified five major themes: (1) choice of social media sites (2) feelings of isolation due to CF; (3) use of social media for medical information; (4) emotional support using social media; and (5) negative experiences using social media. Results indicated that individuals with CF are actively using social media sites for support related to their CF and there is a positive emotional response to social media with increased use and interaction ($p < 0.001$). The most statistically significant influential factors of the use of social media and level of interaction on these sites are the patient's perceived treatment burden ($p = 0.001$) and physical symptoms related to CF requiring therapy, such as the amount of chest therapy ($p = 0.002$).

2.2 Introduction

Cystic fibrosis (CF) is the most common life-limiting, autosomal recessive disorder of Caucasian populations with N. European ancestry, with a frequency of about 1 in 3500 live-births ("2012 Annual Patient Report," 2013). CF is a congenital, chronic condition, primarily affecting the respiratory and digestive systems. CF patients require daily treatments and medications to treat symptoms and prevent disease progression. These treatments are a time consuming, daily burden and patients can find it increasingly difficult to fulfill their aspirations for a "normal" life as a result of the restrictions placed on them by treatment requirements (Badlan, 2006). Such restrictions can cause CF individuals to feel alienated from their peers. As a result, there are a number of CF patients who require life-long social support from other CF patients who may understand and share the restrictions that are placed on their lives due to disease management.

Unfortunately, because cystic fibrosis puts patients at risk for transmittable lung infections, the Cystic Fibrosis Foundation issued an infection prevention and control policy. This policy applies to all individuals with CF and states that only one person with CF may attend any CF Foundation indoor event and must maintain a six-foot distance between CF patients at any outdoor event (Saiman, 2003). This policy discourages and prevents CF patients from attending in-person support groups with other CF patients. As a result of the physical restrictions on direct in-person contact among groups of CF patients, unlike other chronic conditions such as sickle cell disease or diabetes, CF patients cannot receive typical, direct social support from other individuals affected by CF.

The need to connect to other people in similar social situations is an inherent desire that is present in all human beings. Friendships and romantic relationships all stem from this natural yearning to be around and receive support and acceptance from others. However, when a person feels "abnormal" due to a chronic condition such as CF, this desire to connect with others can be compounded. Individuals with CF hope for a normal life, desire long-term relationships, and/or marriage, children, and a good career (Higham et al., 2013). Unfortunately, due to restrictions placed on them by their treatments and illness, CF patients find it increasingly difficult to fulfill their aspirations for a 'normal' life (Badlan, 2006). Adults with CF can have difficulties in developing interpersonal relationships, and as a result, be left isolated and socially maladjusted (Pfeffer et al., 2003).

With the advent of the Internet and social media sites, CF patients have the opportunity to seek and obtain social support about their condition from other patients

without the risk of infection. Social media can be defined as different mediums, with the main categories including blogs, collaborative projects, content communities, and social networking (Kaplan & Haenlein, 2010). Previous studies have found that the use of online social support groups for a chronic condition can promote patient empowerment via the patients' exchange of relevant information, encountering emotional support, sharing experiences, helping others, finding recognition, and amusement (van Uden-Kraan et al., 2009). Social networks can be used to correspond with others on subjects such as the bodily symptoms, clinical diagnosis and treatment options, adverse treatment effects, sources of medical evidence, experiences with individual providers and opinions about their quality (Griffiths et al., 2012). Previous studies have found that online social support programs targeting chronic illness decrease symptoms and improve health behaviors, self-efficacy, and satisfaction with health service (Lorig et al., 2008).

To date, current literature is lacking research that examines adult CF patients' utility of online support groups and social media. The primary objectives of this study include determining the amount of time participants utilize social media for social and emotional support, the participant's motivation for seeking support, the level of support participants received during their use of social media, and the social media sites the participant used for CF-related support. Another objective of this study is to assess the participant's mental and physical health, related to their use of social media as a support system.

Data was collected with the intention of identifying trends between the patient's use of social media and their emotional wellbeing. We hypothesize that there is a positive correlation between the patients' health related quality of life and the amount of time

spent on CF-related social media sites. Specifically, it is expected that patients with poorer health related quality of life are more likely to seek online support groups as a result of feelings of depression or isolation from their peers. There is also expected to be a correlation between the amount of time these patients spend on CF-related social media sites and their perceived value of these sites for CF-related emotional support.

This study will provide healthcare professionals, such as genetic counselors, with insight about whether patients with CF find online support groups and social media sites beneficial to their mental health and emotional wellbeing. The results of this study will be clinically useful to healthcare professionals who may use it to assess the support resources available online for adult cystic fibrosis patients. By gaining a deeper understanding of how CF patients obtain emotional and social support through the use of online social media resources, healthcare professionals may better understand the needs of adult CF patients. Also, by incorporating and recommending the use of social media resources available to CF patients, healthcare professionals may enhance the CF patients' subjective healthcare experience.

2.3 Materials and Methods

This research study collected quantitative and qualitative data from adult patients with cystic fibrosis. Participants were recruited by an invitation to take the survey posted on various social media venues (blogs, websites, Facebook groups, etc.) targeted towards adult CF patients. Adults with cystic fibrosis who use social media as a support network were eligible to participate in this study. Participants had the option to volunteer for a follow-up interview. Individuals who were under the age of eighteen or who have not been diagnosed with CF were excluded from this study.

A request to post a link to the survey was sent out via Facebook and email

(Appendix A) to thirty-seven Facebook groups and blogs, thirty-five of which approved my request (Appendix B). The request explained the purpose of the research study and asked permission to post an invitational letter (Appendix C) and link to participate in an online survey hosted on SurveyMonkey.com on their Facebook group or blog. The survey link was posted on the various sites between September, 2013, and October, 2013, and available for completion until January, 2014.

The online survey (Appendix D) consisted of demographic questions and a series of multiple choice and Likert scale questions designed to assess the patient's Health Related Quality of Life (HRQoL) and the participant's use of social media. Questions from the social, emotional, and treatment burden sections of the Cystic Fibrosis Questionnaire-Revised were used with permission from the author (Appendix E) to assess the patient's Health Related Quality of Life (HRQoL). These questions aimed to adequately capture the broader impact of disease on the patient's physical, social, and psychological functioning measure the patient's emotional wellbeing. Because these questions were pulled from a pre-existing scale, the reliability and consistency was already obtained. The previous reliability coefficient for Emotion was 0.81, Treatment burden was 0.18, and Social was 0.71 (A. L. Quittner, Buu, Messer, Modi, & Watrous, 2005). Cronbach's alpha was performed on these questions prior to finalizing the survey for reliability and consistency, per the original author's request. In our survey, Cronbach's alpha for Emotion was 0.794, Cronbach's alpha for Treatment burden was 0.694, and Cronbach's alpha for Social was 0.584. These reliability coefficients are above or close to the cut off of 0.7, suggesting internal reliability.

The survey also involved questions about social media adapted from Uden-Kraan et al., 2009, a previous study focused on fibromyalgia, arthritis, and breast cancer patient empowerment through use of online support groups (van Uden-Kraan et al., 2009). Initial participant qualification for the survey was determined based on CF status and age: Do you have Cystic Fibrosis (Individuals who answered "No" were disqualified.); What is your age? (Individuals who answered "Under 18 years" were disqualified.)

Participants who did not meet the qualifications were denied access to the remainder of the survey. The participants reported their use of social media, time spent per week on social media, their reasons for seeking online support, and how they feel as a result of use of online support groups. Demographic information was obtained related to age, gender, ethnicity, education level, occupation, etc. The patient's most recent Forced Expiratory Volume (FEV_1), presence or absence of a lung transplant, and pancreatic sufficiency status was also used to assess the severity of the patient's physical condition.

Participants were not required to answer all survey questions, thereby allowing participants to skip questions they were not comfortable answering. All qualifying participants' responses to each question were gathered and included in the analysis of the study. Once participants had completed the survey, they were invited to provide contact information for a volunteer phone interview.

A pilot study was created to obtain participant feedback about the quality and clarity of the survey and interview questions and completed by two qualifying participants. Suggested changes were incorporated before data collection began.

Quantitative analysis of the online surveys was conducted using SPSS version 22.0 statistical software (SPSS Inc., Chicago IL). Analysis of Variance (ANOVA), chi-square,

independent T-tests, and Spearman's Rho analyses were used to determine statistically significant relationships within and between each survey group. Frequencies and percentages were calculated for each question.

Telephone interviews were conducted for the qualitative portion of the study. The follow-up interview contained nine open-ended questions and, with the participant's permission, the answers were recorded for later transcription and identification of themes. The purpose of the follow-up interview is to provide information about the participant's motivation for seeking social support. These follow-up questions provide examples of the participant's positive and negative experiences while using social media for CF-related support. All interviews were recorded using Audacity™, an online voice recording software, and transcribed by the principle investigator for analysis. A structured interview method was used to conduct the interview with a series of predetermined open-ended questions that were aimed at answering the objectives of this study (Appendix F).

Thirty-one survey participants volunteered for the follow up interview. Fifteen of these volunteers were then selected to participate in this follow up interview via stratified random sampling. The principal investigator contacted the participants by telephone during the designated timeframe they requested. International participants were contacted via email. Personal information including names, telephone numbers, and emails were gathered only for the purpose of contacting willing participants and were discarded after the completion of the telephone interview. Qualitative data was reviewed and coded by the principal investigator and overlying themes pertaining to online support groups were identified using standard Grounded Theory methods.

2.4 Results

2.4.1 Participant Demographics. Total participants who completed this survey equaled 121 (N = 121). Six participants were disqualified from survey because they were under 18 years old and 12 participants were disqualified from survey because they were not diagnosed with Cystic Fibrosis (CF) (N = 103). Two thirds of the participants were either between the ages of 18-24 years (30%) or 25-32 years (30%). Respondent demographics are displayed in Table 2.1 and Table 2.2.

Table 2.1 Inclusion patient demographics

		Frequency	Percentage
Does the participant have Cystic Fibrosis?		n = 121	(%)
	Yes	109	90
	No	12	10
Age (of individuals with CF)		n=109	(%)
	Under 18 years	6	6
	18-24 years	33	30
	25-32 years	33	30
	33-40 years	15	14
	41-48 years	10	9
	49-56 years	5	5
	57-66 years	7	6
	67-100 years	0	0

The majority of participants were Caucasian (n = 100, 97%) females (n = 86, 83%). Participants were relatively equally distributed among education level, work status, marital status, and age range (Table 2.2).

Table 2.2 Qualifying Participant Demographics (*N=103)*

		Frequency	Percentage
Gender		*n* = 103	(%)
	Male	17	17
	Female	86	83
Marital Status		*n* = 103	
	Single/Never Married	25	24
	In a relationship	26	25
	Married	41	40
	Widowed	1	1
	Divorced	5	5
	Separated	2	2
	With a partner	3	3
Ethnicity		*n* = 103	
	Caucasian	100	97
	African American	0	0
	Hispanic	0	0
	Asian	1	1
	Native American	3	3
Education level		*n* = 101	
	Did not attend school	0	0
	Did not finish high school	6	6
	Completed high school/GED	15	15
	Some college education	31	31
	Associate's degree	14	14
	Bachelor's degree	23	23
	Graduate school	12	12
Work Status		*n* = 103	
	Attending school outside home	24	23
	Taking educational courses at home	6	6
	Seeking work	2	2
	Working full/part time	39	38
	Full time homemaker	11	11
	Not attending school/working due to my health	38	37
	Not working for other reasons	5	5

The majority of participants were diagnosed with CF either at birth (*n* = 29, 29%) or before one year of age (*n* = 30, 30%), have not received a lung transplant (*n* = 92, 92%), are pancreatic insufficient (*n* = 80, 80%), have tested negative for the bacteria *B. cepacia* (n = 89, 92%), and have tested positive for the bacteria *P. aeruginosa* (*n* = 89, 90%) in the past. The majority of participants used coughing as a therapy to clear their lungs (*n* = 73, 72%) twice a day (*n* = 47, 47%). Participants were relatively equally distributed among FEV_1 percent of predicted value and number of hospitalizations in the past year (Table 2.3).

Table 2.3 Participant Demographics regarding Cystic Fibrosis (*N=103)*

		Frequency	Percentage
At what age were you diagnosed with CF?		*n* = 100	(%)
	At birth	29	29
	Less than 1 year	30	30
	1-5 years	14	14
	6-10 years	6	6
	11-20 years	7	7
	21-30 years	3	3
	31-40 years	4	4
	41-50 years	3	3
	50 or older	4	4
What was your most recent FEV_1 percent of predicted measurement?		*n* = 86	
	>90%	12	14
	80-89%	17	20
	70-79%	9	10
	60-69%	6	7
	50-59%	10	12
	40-49%	18	21
	30-39%	7	8
	20-29%	6	7
	10-19%	1	1
	Less than 10%	0	0
Lung transplant		*n* = 100	
	Yes	8	8
	No	92	92
Pancreatic Insufficient		*n* = 100	
	Yes	80	80
	No	20	20
Tested positive for Burkholderia cepacia (B. cepacia)		*n* = 97	
	Yes	8	8
	No	89	92
Tested positive for Pseudomonas aeruginosa (P. aeruginosa)		*n* = 99	
	Yes	89	90
	No	10	10
Type of therapy used (check all that apply)		*n* = 101	
	Coughing	73	72
	Chest Physical Therapy	36	36
	Oscillating Positive Expiratory Pressure device	32	32
	"Vest" therapy	55	54
	Autogenic drainage	15	15
	Breathing techniques	39	39
	Cardio exercise	68	68
How often do you perform "chest therapy?"		*n* = 100	
	Weekly	0	0
	2-3 times per week	8	8
	Once a day	25	25
	Twice a day	47	47
	Only when sick or in the hospital	7	7
	I do not perform chest therapy	13	13
How often were you hospitalized in the past year?		*n* = 100	
	I have not been hospitalized in the past year	38	38
	Once	28	28
	Twice	10	10
	Three times	10	10
	Four times	6	6
	More than 5 times	8	8

The majority of participants used online social media sites dedicated to individuals with CF (*n* = 89, 97%), using primarily Facebook groups related to CF (*n* =

88, 96%), and interacted with other CF patients on these sites (n = 78, 85%). The individuals who post on these sites will be referred to as "posters." Individuals who only read these sites (n = 14, 15%) will be referred to as "lurkers" (Table 2.4).

Table 2.4 Social Media Interaction

	Frequency	Percentage
Do you use online support groups and social media sites dedicated to individuals with cystic fibrosis for any reason?	n = 92	(%)
Yes	89	97
No	3	3
What type of online support groups do you use related to CF? (Please check all that apply)	n = 92	
Facebook groups	88	96
Myspace	1	1
Twitter	15	16
Google+	10	11
Youtube	18	20
Blogs	35	38
Online support groups (ex. CysticLife, Cysticvoices)	34	37
Online chat rooms	1	1
Do you interact with other CF patients on these sites?	n = 92	
Yes, I post on these sites.	78	85
No, I just read these sites.	14	15

2.4.2 Participant's Use of Social Media

Participants were asked a series of Likert scale questions about their interaction on social media with other users. On Likert scale questions of one (less than two hours) to five (more than 20 hours), participants reported that they spent approximately less than two hours per week on online support groups or social media specifically for CF (Figure 2.1) and two to seven hours per week on all online support groups or social media (CF related and non-CF related) (Figure 2.2).

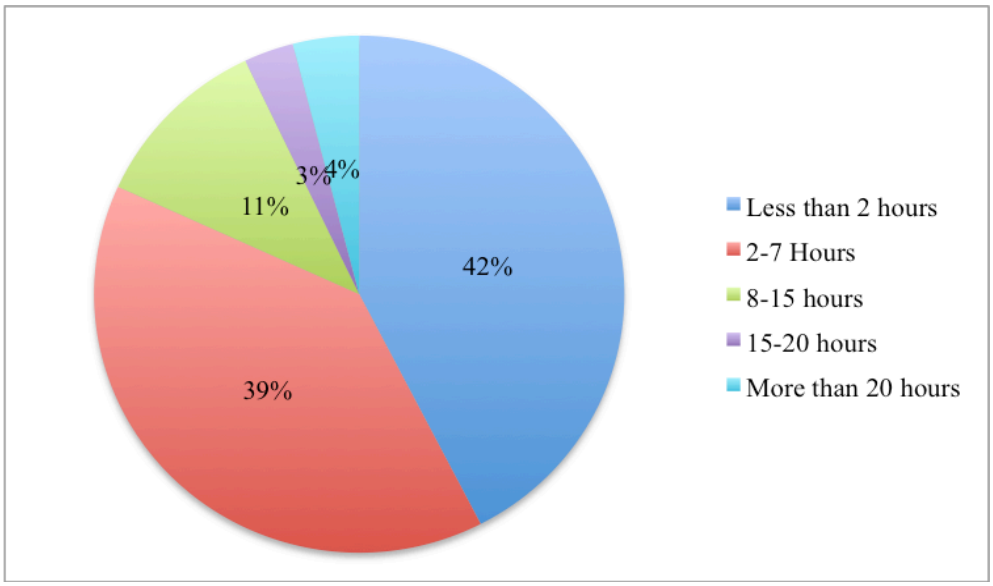

Figure 2.1 **Number of hours participants spent on social media related to CF per week**

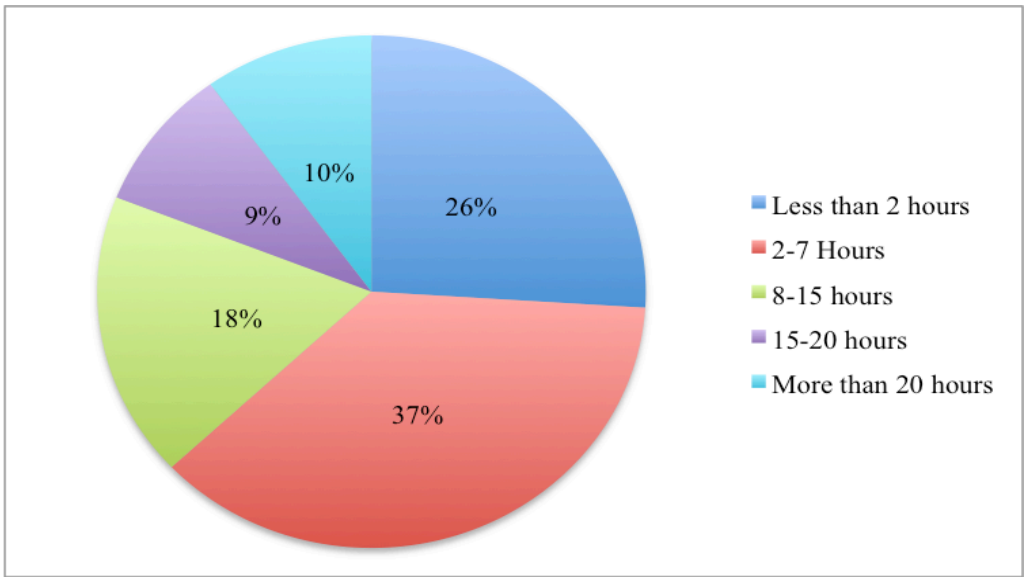

Figure 2.2 **Number of hours participants spent on all online support groups or social media per week**

On a Likert scale question of one (a few times per month) to five (twice or more per day), participants reported that they spent between 2-7 hours per week online at various social media sites to access information, news, or support for CF (M = 2.78, SD =

1.48) (Figure 2.3). A "social media usage score" was created for each participant to calculate how much they used social media based on these three questions (Table 2.5).

Table 2.5 Likert Scale-Social Media Usage Score

Statement	*n*	Mean Score	Standard Dev
How much time do you spend on online support groups or social media specifically for CF per week [a]	90	1.89	1.10
How much time do you spend on all online support groups or social media per week (CF related and non-CF related) [a]	92	2.40	1.24
How often do you get online at various social media sites to access information, news, or support for CF [b]	90	2.78	1.48
Average Social Media Usage Score		2.35	1.05

[a] Range of answers: 1 = Less than 2 hours, 2 = 2-7 hours, 3 = 8-15 hours, 4 = 15-20 hours, 5 = More than 20 hours

[b] Range of answers: 1 = A few times per month, 2 = Weekly, 3 = Two to three times per week, 4 = Daily, 5 = Twice or more daily

Participants were asked a series of Likert scale questions of one (seldom to never) to four (often) about their interaction on social media with other users. Overall, on average, participants only interacted with other members of these sites sometimes. A "social media interaction score" was created for each participant to calculate how active they were on social media with other support group users. This score derived from the average of all five questions related to their interaction on social media (Table 2.6).

Table 2.6 Likert Scale-Social Media Interaction Score

Statement	*n*	Mean Score	Standard Dev
Members of these sites start a private conversation with me.[c]	91	1.88	0.99
Members of these sites reassure me.[c]	91	2.37	1.02
Members of these sites offer me advice.[c]	91	2.44	1.03
Members of these sites confide in me.[c]	91	2.12	1.10
Members of these sites ask me for my help or advice.[c]	90	2.33	0.97
Average Social Media Interaction score [c]		**2.22**	**0.85**

[c] Range of scores: 1 = Seldom to Never, 2 = Sometimes, 3 = Regularly, 4 = Often

Participants were also asked a series of Likert scale questions about their emotional response to using social media for CF-related support. On Likert scale

questions of one (seldom to never) to four (often), participants reported their feelings when they used these social media sites (Table 2.7).

Table 2.7 Likert Scale-Social Media Response Scores

Statement	*n*	Mean Score	Standard Dev
When I use these sites, I experience the sense of "not being the only one."[c]	89	3.24	0.87
When I use these sites, I experience the feeling that I am not so bad off after all.[c]	90	2.97	0.95
When I use these sites, I feel that I can share my experiences with my illness with others.[c]	90	3.17	0.90
Average Social Media Response Score[c]		**3.12**	**0.02**

[c] Range of scores: 1 = Seldom to Never, 2 = Sometimes, 3 = Regularly, 4 = Often

On Likert scale questions of one (completely disagree) to five (completely agree), participants reported their feelings since they began to use social media sites related to CF (Table 2.8). A "social media emotional response score" was created for each participant to calculate the user's response to using these online support groups. The average score derived of all Likert scale questions related to their emotional response to their use of social media was 3.62 out of 5.

Table 2.8 Likert Scale-Social Media Emotional Response Score

Statement	*n*	Mean Score	Standard Dev
Since I began to use these sites, I feel that I am more knowledgeable about which questions to ask my healthcare providers[d]	90	3.62	1.08
Since I began to use these sites, I feel that I am more open about my cystic fibrosis with others[d]	90	3.56	1.07
Since I began to use these sites, I feel I am more capable at emotionally coping with my CF[d]	90	3.38	1.04
Since I began to use these sites, I feel more emotionally in control over my CF[d]	90	3.28	1.07
Since I began to use these sites, I have less faith in the future.*[d]	90	1.98	1.01
Since I began to use these sites, I feel more positive about my life with CF.[d]	89	3.60	1.01
Since I began to use these sites, I have more faith in the future.[d]	90	3.56	0.97
Since I began to use these sites, I feel less emotionally in control over my CF*[d]	89	2.17	1.11
Since I began to use these sites, I have a greater sense of worth.[d]	90	3.34	1.06
Since I began to use these sites, I feel less lonely.[d]	89	3.67	1.01
Since I began to use these sites, I have made new social contacts.[d]	90	4.01	1.13
Average Emotional Response score[d]		**3.62**	**0.71**

[d] Range of answers: 1 = Completely disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Completely agree

***item was reverse coded during scoring** (5=1, 4=2, 2=4, 1=5)

2.4.3 Participant's Emotional Well-Being Related to Cystic Fibrosis

Patients were then asked a series of Likert scale questions to evaluate their emotional well-being. These questions were extracted from the Cystic Fibrosis Questionnaire-Revised (CFQ-R), with permission from the author. Three different well-being "scores" were created based on participant answers: an emotional well-being score, social well-being score, and treatment burden score.

On Likert scale questions to evaluate the participant's emotional well-being, as one (always) to four (never) and one (very true) to four (very false), participants reported how often they experienced negative emotions in the past few weeks (Table 2.9). The average participant emotional well-being score was calculated using the equation TOTAL = (Sum of scores - 5)/15 = ___ × 100, as directed by the CFQ-R scoring manual. The

average emotional well-being score was 65.8 out of 100. A higher emotional well-being score can be interpreted as having a higher emotional well-being.

Table 2.9 Likert Scale-CFQR "Emotional Well-Being" Score

Statement "During the past two weeks indicate how often:"	*n*	Mean Score	Standard Dev
I felt worried[e]	88	2.81	0.88
I felt useless[e]	89	3.40	0.88
I felt sad[e]	88	2.99	0.84
I often feel lonely[f]	89	2.91	1.04
It is difficult to make plans for the future (for example going to college, getting married, advancing in a job, etc.)[f]	89	2.76	1.09
Average emotional well-being score[g]		**65.81**	**23.50**

[e] Range of answers: 1 = Always, 2 = Often, 3 = Sometimes, 4 = Never
[f] Range of answers: 1 = Very true, 2 = Somewhat true, 3 = Somewhat false, 4 = Very false
[g] Range of answers: 1-100
***item was reverse coded during scoring** (4=1, 2=3, 3=2, 1=4)

Participants were then asked a series of Likert scale questions, as one (very true) to four (very false) to evaluate their social well-being in the past two weeks (Table 2.10). The average participant social well-being score was calculated using the equation TOTAL = (Sum of scores - 6)/18 = ___ × 100, as directed by the CFQ-R scoring manual. The average social well-being score was 54.4 out of 100. A higher social well-being score can be interpreted as having an active social life.

Table 2.10 Likert Scale-CFQR "Social Well-Being" Score

Statement "During the past two weeks indicate how often:"	*n*	Mean	Standard Dev
I have to stay at home more than I want to[f]	88	2.47	1.14
I feel comfortable discussing my illness with others*[f]	89	1.98	0.95
People are afraid that I may be contagious[f]	88	2.67	0.96
I get together with my friends a lot*[f]	89	2.26	1.02
I think my coughing bothers others[f]	89	1.97	0.92
I feel comfortable going out at night*[f]	89	2.04	1.03
Average Social Well-Being score[g]		**54.36**	**19.21**

[f] Range of answers: 1 = Very true, 2 = Somewhat true, 3 = Somewhat false, 4 = Very false
[g] Range of answers: 1-100

***item was reverse coded during scoring** (4=1, 2=3, 3=2, 1=4)

Participants were asked a series of Likert scale questions, of one (not at all) to four (a lot) to determine their perceived treatment burden (Table 2.11). The average

participant perceived treatment burden score was calculated using the equation TOTAL = (Sum of scores-3)/9 = _____ × 100, as directed by the Cystic-Fibrosis Questionnaire Revised scoring manual. The average treatment burden score was 46.34 out of 100. A lower treatment well-being score can be interpreted as having a higher treatment burden.

Table 2.11 Likert Scale-CFQR "Treatment Well-Being" Score

Statement: "During the past two weeks indicate how often:"	*n*	Mean Score	Standard Dev
To what extent do your treatments make your daily life more difficult?*[h]	89	2.65	0.83
How much time do you currently spend each day on your treatments?[i]	89	2.01	0.94
How difficult is it for you to do your treatments (including medications) each day?*[h]	89	2.20	0.91
Average Treatment burden score[g]		**46.34**	**23.39**

[h] Range of answers: 1 = Not at all, 2 = A little, 3 = Moderately, 4 = A lot
[i] Range of answers: 1 = A lot, 2 = Some, 3 = A little, 4 = Not very much
[g] Range of answers: 1-100
***item was reverse coded during scoring** (4=1, 2=3, 3=2, 1=4)

2.4.3 Quantitative Analysis of Participant's Use of Social Media

Data was analyzed via comparative statistical tests. Chi square tests were used to determine independence and assess whether there is an association between two categorical variables. There was a statistically significant association between the pancreatic insufficiency and the patient's use of social media χ^2 (1, N = 91) = 4.70, p = .03. Lung transplant status was associated with the participant's poster vs. lurker status χ^2 (1, N = 91) = 5.91, p = .02. There was an association found between pancreatic insufficiency and poster vs. lurker status χ^2 (1, N = 91) = 3.16, p = .08, an association between *P. aeruginosa* status and social media use χ^2 (1, N = 90) = 3.16, p = .08), and an association between work status and social media use χ^2 (7, N = 91) = 2.03, p = .06, although these associations were not statistically significant. No other statistically significant associations were found (Table 2.12).

Table 2.12 Association of Demographics on Social Media Use and Poster vs. Lurker status

	Participant use social media	Poster vs. Lurker status
Gender		
χ^2	0.120	0.000
Sig.	0.730	0.997
df	1	1
N	91	91
Work Status		
χ^2	2.030	1.596
Sig.	0.061	0.148
df	7	7
N	91	91
Education level		
χ^2	0.674	0.478
Sig.	0.671	0.823
df	6	6
N	90	90
Ethnicity		
χ^2	0.143	0.761
Sig.	0.931	0.684
df	2	2
N	91	91
Marital status		
χ^2	8.311	3.910
Sig.	0.216	0.689
df	6	6
N	92	92
Lung transplant		
χ^2	0.219	5.913
Sig.	0.640	0.015*
df	1	1
N	91	91
Pancreatic insufficient		
χ^2	4.702	3.160
Sig.	0.030*	0.075
df	1	1
N	91	91
Positive for *B. cepacia*		
χ^2	0.227	1.461
Sig.	0.634	0.227
df	1	1
N	88	88
Positive for *P. aeruginosa*		
χ^2	2.290	3.219
Sig.	0.130	0.073
df	1	1
N	90	90

*Statistically significant relationship

Spearman's rho correlation coefficient was used to determine if there is a correlation between two ordinal variables. A statistically significant negative correlation was found between participant's age and FEV_1 percent of predicted, meaning as the participant's age increased, their FEV_1 percent of predicted would decrease, r (86) = -0.28, p = .01. There was also a negative correlation between the number of times the

participant had been hospitalized in the past year and their FEV_1 percent of predicted, meaning more hospitalizations are associated with a lower FEV_1 percent of predicted, r (78) = -0.36, $p < .01$. No statistically significant correlation between participant FEV_1 percent of predicted and amount of chest therapy, r (75) = 0.63, $p = .59$, and no statistically significant correlation between amount of chest therapy and number of hospitalizations, r (79) = 0.14, $p = .22$.

Participant hospitalizations were also negatively correlated with participant treatment burden scores r (81) = -0.34, $p < .01$ and emotional well-being scores, r (81) = -0.39, $p < .001$. Participant's age was negatively correlated with participant social well-being score, r (89) = -0.24, $p = .03$. Participant treatment burden score was negatively correlated with the amount of chest therapy the participant performed, r (77) = -0.32, $p < .01$. There was no statistically significant correlation between age and number of hospitalizations, r (92) = -0.03, $p = .81$, or age and amount of chest therapy, r (87) = 0.04, $p = .73$.

Participant social well-being score was positively correlated with participant treatment burden score, r (89) = 0.44, $p < .001$, and participant emotional well-being score, r (89) = 0.63, $p < .001$. Participant emotional well-being score was positively correlated with participant treatment burden score, r (89) = 0.37, $p < .001$. Participant's FEV_1 percent of predicted was also positively correlated with participant's treatment burden score, r (77) = 0.29, $p = .01$, as well as participant's social well-being score, r (77) = 0.31, $p = .005$. The number of patient hospitalizations was negatively correlated with treatment burden, r (81) = -0.34, $p = 0.002$, and emotional well-being, r (81) = -0.39, $p < 0.001$. The number of patient hospitalizations was also negatively correlated with social

well-being but the correlation was not statistically significant, r (81) = -0.20, p = 0.08 (Table 2.13).

Table 2.13 Correlation Between CF-Related "Well-Being" scores and FEV_1 percent of predicted, Age, and Hospitalizations

	Social Well-Being	Treatment burden	Emotional Well-Being
Social Well-Being Correlation Coefficient	1.00	0.439**	0.628**
Sig (2-tailed)		< .001	< .001
N	89	89	89
Treatment burden Correlation Coefficient	0.439**	1.00	0.369**
Sig (2-tailed)	< .001		< .001
N	89	89	77
Emotional Well-Being Correlation Coefficient	0.628**	0.369**	1.00
Sig (2-tailed)	< .001	< .001	
N	89	77	89
FEV_1 Correlation Coefficient	0.314**	0.289*	0.159
Sig (2-tailed)	0.005	0.011	0.167
N	77	77	77
Hospitalizations Correlation Coefficient	-0.196	-0.336**	-0.385**
Sig (2-tailed)	0.079	0.002	< .001
N	81	81	81
Age Correlation Coefficient	-0.237	-0.093	0.159
Sig (2-tailed)	0.025*	0.384	0.167
N	89	89	77

*Statistically significant correlation
**Strongly significant statistical correlation

More importantly, participant social media usage score was strongly correlated with participant social media interaction score, r (90) = 0.55, p < .001, as well as participant social media emotional response score, r (90) = 0.51, p < .001. Participant social media interaction score is strongly correlated with participant social media emotional response score, r (90) = 0.63, p < .001 (Table 2.14). No additional statistically significant correlations were identified for the survey group.

Table 2.14 Correlation Between Social Media scores and Age

	Social Media Usage	Social Media Interaction	Social Media Emotional Response	Age
Social Media Usage				
Correlation Coefficient	1.00	0.546**	0.507**	0.122
Sig (2-tailed)		< .001	< .001	0.247
N	92	91	90	92
Social Media Interaction				
Correlation Coefficient	0.546**	1.00	0.632**	0.037
Sig (2-tailed)	< .001		< .001	0.725
N	91	91	90	91
Social Media Emotional Response				
Correlation Coefficient	0.507**	0.632**	1.00	0.098
Sig (2-tailed)	< .001	< .001		0.358
N	90	90	90	90

*Statistically significant correlation
**Strongly significant statistical correlation

Participant treatment burden score was negatively correlated with social media usage score, r (89) = -0.34, p = .001, and social media interaction score, r (88) = -0.31, p = .003. Participant social media usage score was negatively correlated with the amount of participant chest therapy, r (80) = -0.34, p = .002, amount the participant interacted with others on social media, r (80) = 0.39, p < 0.001, and social media emotional response score was correlated with the amount of participant chest therapy, r (79) = 0.25, p = .03 (Table 2.15).

Table 2.15 Correlation Between Social Media scores and CF-related well-being scores

	Social Well-Being Score	Emotional Well-Being Score	Treatment Burden Score	Chest Therapy	FEV_1
Social Media Usage					
Correlation Coefficient	-0.198	-0.197	-0.334**	0.336**	-0.151
Sig (2-tailed)	0.063	0.065	0.001	0.002	0.184
N	89	89	89	80	79
Social Media Interaction					
Correlation Coefficient	-0.175	-0.065	-0.311**	0.389**	-0.135
Sig (2-tailed)	0.103	0.545	0.003	< .001	0.238
N	88	88	88	80	78
Social Media Emotional Response	-0.116	-0.022	-0.189	0.249*	-0.040
Correlation Coefficient	0.281	0.837	0.078	0.027	0.730
Sig (2-tailed)	88	88	88	79	77
N					

*Statistically significant correlation
**Strongly significant statistical correlation

ANOVA tests were run comparing Likert scale questions (including social media and well-being scores) to demographic information of the participants including age,

education level, gender, ethnicity, work status, and CF-related health information (Table 2.16). ANOVA tests were carried out to analyze if demographic information of the participants including age, FEV_1 percent of predicted, frequency of chest therapy, number of hospitalizations, and well-being (treatment burden, emotional, and social) scores influenced if participants were social media users or non social media users. Results showed that use of social media was dependent on the amount of chest therapy the participant performed per week, F (2, 1) = 3.51, p = .03. No additional statistically significant relationships were identified for the survey group.

Table 2.16 Influence of Demographics on Social Media vs. Non-social Media users

	Does the participant use social media?
Age	
F	1.231
Sig.	0.296
df	2
FEV_1	
F	0.106
Sig.	0.900
df	2
Chest Therapy	
F	3.506
Sig.	0.034*
df	2
Number of Hospitalizations	
F	1.391
Sig.	0.254
df	2
Social Well-Being Score	
F	2.062
Sig.	0.155
df	1
Emotional Well-Being Score	
F	1.362
Sig.	0.246
df	1
Treatment burden Score	
F	0.473
Sig.	0.493
df	1
Social Usage Score	
F	0.949
Sig.	0.332
df	1

*Statistically significant relationship

ANOVA tests were carried out to analyze if demographic information of the participants including age, FEV_1 percent of predicted, frequency of chest therapy, number

of hospitalizations, well-being (treatment burden, emotional, and social) scores, and social media (usage, interaction, and emotional response) scores influenced if participants were "posters" or "lurkers" (Table 2.17). Results showed that the participant's "poster" vs. "lurker" status was dependent on the amount of chest therapy the participant performed per week, F (2, 1) = 7.79, p = .001. Poster vs. lurker status was dependent on the participant's treatment burden score, F (1,1) = 7.00, p = .01. Poster vs. lurker status was also strongly dependent on the participant's social media usage score, F (1, 1) = 12.257, p = .001, strongly dependent on the participant social media interaction score, F (1, 1) = 28.375, $p <$ .001, and strongly dependent on the participant's social media emotional response score F (1, 1) = 19.69, $p <$ .001. No additional statistically significant relationships were identified for the survey group.

Table 2.17 Influence of Demographics on Poster vs. Lurker status

	Poster vs. Lurker status
Age	
F	0.775
Sig.	0.463
df	2
FEV_1	
F	0.044
Sig.	0.957
df	2
Chest Therapy	
F	7.788
Sig.	0.001**
df	2
Number of Hospitalizations	
F	0.323
Sig.	0.725
df	2
Social Well-Being Score	
F	3.006
Sig.	0.086
df	1
Emotional Well-Being Score	
F	0.694
Sig.	0.407
df	1
Treatment burden Score	
F	7.003
Sig.	0.010*
df	1
Social Usage Score	
F	12.257
Sig.	0.001**
df	1
Social Media Interaction Score	
F	28.375
Sig.	< .001**
df	1
Social Emotional Response Score	19.691
F	< .001**
Sig.	1
df	

*Statistically significant relationship
**Strongly significant statistical relationship

ANOVA tests were carried out to analyze if demographic information of the participants including gender, ethnicity, work status, education level, marital status, lung transplant status, pancreatic insufficiency, and previously testing positivie for bacteria *B. Cepacia* or *P. Aeruginosa* influenced social media (usage, interaction, and emotional response) scores (Table 2.18). Patient's test status for the bacteria *P. Aeruginosa* does influence social media interaction score, F (2, 1) = 4.73, p = 0.01. Work status did influence social media usage score, F (7, 1) = 2.03, p = .06, but this relationships was not

statistically significant. There were no other statistically significant relationships identified.

Table 2.18 Influence of Demographics on Social Media Scores

	Social Media Usage Score	Social Media Interaction Score	Social Media Emotional Response
Gender			
F	0.120	0.000	0.158
Sig.	0.730	0.997	0.692
df	1	1	1
Work Status			
F	2.030	1.596	1.624
Sig.	0.061	0.148	0.140
df.	7	7	7
Education level			
F	0.674	0.478	0.572
Sig.	0.671	0.823	0.752
df	6	6	6
Ethnicity			
F	0.713	0.423	0.065
Sig.	0.547	0.737	0.978
df	3	3	3
Marital status			
F	1.433	1.061	0.383
Sig.	0.212	0.393	0.888
df	6	6	6
Lung transplant			
F	0.417	0.766	1.496
Sig.	0.660	0.468	0.230
df	2	2	2
Pancreatic insufficient			
F	0.742	1.144	1.621
Sig.	0.479	0.323	0.204
df	2	2	2
Tested positive for *B. cepacia*			
F	0.696	0.384	1.759
Sig.	0.501	0.682	0.178
df	2	2	2
Tested positive for *P. aeruginosa*			
F	0.136	4.727	0.420
Sig.	0.873	0.011*	0.658
df	2	2	2

*Statistically significant relationship
**Strongly significant statistical relationship

2.4.4 Qualitative Review of Participant's Use of Social Media

Qualitative results were collected via phone-interview transcripts and written-in responses to open-ended questions on the initial online survey. Thirty-nine participants completed the "other comment" response section of the original survey and 32 participants volunteered for follow-up telephone interviews. Fifteen of these volunteers were selected for follow-up telephone interviews via stratified random sample. The length of these interviews ranged between six and18 minutes. After transcription of the

interviews, the grounded theory method was used to reveal five major qualitative themes: (1) choice of social media sites; (2) feelings of isolation due to CF; (3) use of social media for medical information; (4) emotional support using social media; and (5) negative experiences using social media. These themes were each broken down further into sub-themes. All themes include a mixture of written-in and phone-interview responses.

Theme 1: Choice of Social Media Sites

The first theme, "choice of social media sites," was broken down into two subcategories: amount of people using the site and convenience. Participants were asked, "Which social media sites do you use? Why did you choose these specific sites?" The majority (75%) of the participants used Facebook for CF-related support. Others used blogs, Twitter, Instagram, or CF-related websites like CysticLife.org. Participants who use Facebook for CF-related support stated that they chose these Facebook based on the number of group members or convenience. One participant commented that she chose the largest CF group on Facebook due to the over 8000 members. Another participant stated that she chose the website CysticLife.org because "It seemed to have the most members and it was really active compared to other sites." Others chose Facebook groups because, as one participant stated, "I was already signed up...It was convenient." Another participant mentioned that she is able to access Facebook on her phone, which allows her to log on to groups for a quick interaction throughout the day. Three participants between the ages of fifty and sixty years mentioned that their choice of Facebook as a support group, as opposed to other online sites, was related to their lack of knowledge of the

Internet. One woman said, "I tried to get into one of the sites…I can't get in…I know they are forums and maybe I can't figure out how to get in them."

Theme 2: Feelings of Isolation due to CF

The second theme, "Feelings of Isolation due to CF," was broken down into three subcategories: the CF Foundation infection control guidelines, feelings of being alone, and the ability to relate to others with CF. Throughout the follow-up interview, the majority (66%) of participants mentioned feeling isolated due to their CF. Almost all of the participants attributed this feeling to the CF Foundation's infection control policy which discourages CF patients from direct contact with one another in an effort to eliminate the spread of bacterial infections. One male participant stated, "My doctors said I can't be around other people with cystic fibrosis." A woman stated, "I think you feel really isolated having CF because you aren't allowed to have face to face contact and going on these sites it's almost the second best to face to face contact." The majority of participants (53%) used the words "alone" or "isolated" in their interview. Another woman said, "Without [social media], I would feel alone. So alone."

Participants described that social media allows them to interact with other people they can relate to about their disease. As one woman stated, "Someone knows exactly what you're going through…How every day you're fighting this disease. You never get a break." Another younger male participant said, "It's nice to know there are other people out there going through the same weird thing I deal with…It's a place where you can fully be yourself, I guess."

Theme 3: Use of Social Media for Medical Information

Another theme throughout the follow up interviews was the use of social media for medical information. Participants shared many stories about posting medical questions about CF on the online support groups in hopes of having other members respond. Reported medical topics posted included a range of topics such as the side effects of newly prescribed medications or treatments, questions about pregnancy with CF, and the genetics of CF. One woman shared:

> I was trying to find a woman who had CF and had children…Was there anybody out there like that? I knew it was possible but I didn't know anybody…That's what lead me to a specific blog…It was encouraging because that's something I want one day and I see other people are doing it, despite problems.

Patients reported browsing these social media sites before a doctor's appointment to see if there were any new treatments or medications they could discuss with their own doctor. For example, one woman shared that looking on the social media groups before a doctor's appointment helped her narrow down the questions she would ask her doctor. Another female participant had digestive issues and another individual with CF suggested she should ask her doctor about pro-biotics, which eliminated her digestive problems.

In addition to discussing medical issues, these online social media groups are used for fundraising projects for the CF Foundation. One participant recounted:

> A girl decided to put a big art piece together and through social media she was able to reach out to us and mail us a piece of canvas in which we were

able to create an art piece and mail it back to her. She put them all together and auctioned them off. The proceeds all went towards CF.

Another participant shared, "I know there's one girl who started a drive to collect unused medications they were sending to a clinic in Mexico. They took it down to a clinic that didn't have money for supplies."

Theme 4: Emotional Support Using Social Media

By far, the most common theme throughout the follow up interviews was the exchange of support on these social media sites related to CF (60%). This theme can be broken down into two subcategories: giving support to others (40%) and receiving support (40%).

The first subcategory, "Providing support to others," was a common topic that came up in interviews. When asked, "What motivates you to log on to these social media sites," participants responded that a large motivator is using the social media sites to encourage others with CF (53%). One 47 year-old female participant stated, "I think if you can help someone out that kind of like, breeds. Just like negativity breeds. I believe so does this type of caring for each other." Providing support for others includes sharing stories and being a positive example for other people with CF. Many older patients mentioned that they post their own stories and befriend and mentor younger CF'ers (nickname used in the community when referring to another individual with CF) through these sites. One older woman responded, "[What motivates me is] To give those an idea that CF isn't the disease it used to be. The outlook was dreary and dim [but] there are a lot of things I am able to do even with lung disease."

The second subcategory in the theme of Emotional Support, "Receiving support from others," was also a reoccurring topic throughout the interviews. In response to the statement, "How do you feel when you use the sites for support related to CF?" one participant replied, "It helps to support me. Every time I get any support, I feel a little more okay with my CF and my life." A common subject was also being inspired by other people with CF (47%). One participant stated, "There have been times where I've been really depressed and I go on there and see someone write about being in the hospital and my problems become minimal compared to…seeing these kids fight, work out, seeing them keep pushing…Their hope."

Theme 5: Negative Experiences Using Social Media

In contrast to the positive response to social media for support, a number of participants expressed their dissatisfaction with using social media for support related to CF. These negative experiences can be categorized as: "Internet trolls," arguing/complaining, and feeling overwhelmed.

The first subcategory, "Internet trolls," was described by one participant as, "Someone who instigates trouble in a group...[these] people bully online." Multiple participants (33%) described incidents where a user will pretend to have CF and join the online support groups to receive support. These participants emphasized that users of the online support groups should use caution (67% and 1 write in answer) and, as one man stated, "Don't let them bring you down."

Another complaint about using social media for support was the amount of arguing (33%) and complaining (20%) that takes place on these online support groups. One young man described it as "A lot of CF'ers, when they're hospitalized, they're

frustrated and angry. [They] don't want to be there and are angry at the world and post on CF feeds like 'I hate this or that.'" Some participants who had ceased using social media for support related to their CF described this as being very discouraging.

However, the most common (53% and two write-in answers) negative experience using social media was described as feeling overwhelmed by the declining health of other users. A common occurrence in the social media groups is for users to form bonds over their CF and become friends. When their friend has a major health crisis, participants described being overcome with feelings of loss and grief. The loss of a friend with CF can also remind the social media user of their own mortality and disease. As one participant stated, "You see people not doing so well…that can be upsetting. That's a possibility some day I might be in." Participants described that when they are feeling overwhelmed, they will take breaks from social media for a period of time. As one participant described, "This got too depressing for me, so I seriously cut back on the number of [groups] and time I spend on support groups for CF…I find it much too difficult."

2.5 Discussion

The present study explored the use of social media by adults with CF and the impact of both physical and emotional well-being on their use of social media. Throughout this study, social media has proven to be a useful resource for support for adults with CF. Participants shared how often they use social media, what sites they use for support, and shared their feelings and experiences with social media. In general, participants mainly used Facebook groups, blogs, and websites devoted to individuals

with CF for support related. This was expected given that the links were posted on several social media sites.

2.5.1 Social Media Use for Support We found that the majority of participants reportedly used online support groups devoted to social media less than two hours per week and accessed social media sites for information, news, and support for CF two to seven hours per week. This was significantly less time spent on social media compared to previous studies of individuals with a chronic health condition, such as physical disability, in which participants reported one to ten hours per week, or diabetes, in which the majority of participants reported using social media daily (Obst & Stafurik, 2010; Shaw & Johnson, 2011; Shpigelman & Gill, 2014). Compared to traditional support venues, such as speaking with a genetic counselor or attending an in person support group, which may only provide a few hours of support monthly or even yearly, social media allows individuals to access support more often (Edwardsen et al., 2013; Obst & Stafurik, 2010).

The majority of our participants used Facebook as a social media site for CF-related support. This can be attributed to the fact that our survey link was posted predominantly on Facebook groups related to CF. However, according to the Pew 2013 Social Media Update, 71% of adults are Facebook users and Facebook is popular among a diverse range of demographic groups (Duggan & Smith, 2014). This leads us to believe that the majority of online support related to CF is most likely via Facebook.

One objective of our study was to determine if patients interacted through social media sites or just read these sites for support. These categories were previously designated as a "poster" (patients who interact through these sites with others) or

"lurkers" (patients who only read the sites) (Setoyama et al., 2011). We found that 85% of participants in this study were considered "posters." This suggests a high degree of communication on the social media sites related to CF compared to previous studies where 49% of participants with breast cancer were considered "posters" on social media sites related to breast cancer. We theorize that this rise in user interaction may be due to the chronic nature of CF, compared to the isolated case of breast cancer during a patient's lifetime. Patients diagnosed with breast cancer are diagnosed with cancer later in life and usually only require treatments for a specific duration of time to treat their symptoms before they eventually go into remission. Individuals with CF require treatments every day throughout their entire lives to manage their symptoms, for which there is currently no cure. Individuals with CF are likely to be more comfortable interacting with others about their symptoms and treatments, which they have become accustomed to over their lifetime.

The study by Setoyama et. al. found that posters felt they received more benefits from online communities than lurkers did, including emotional support, helping other patients, and expressing their emotions (Setoyama et al., 2011). We found a strong correlation between poster vs. lurker status and social media usage score, social media interaction score, and social media response score. This suggests that individuals with CF who are "posters" are using social media and interacting with other individuals on these sites more frequently than "lurkers." As a result of the increased use and interaction, "posters" have a stronger positive emotional response and feel a stronger sense of support, which concurs with previous studies findings (van Uden-Kraan et al., 2009).

Our study found a strong correlation between the amount of time participants devoted to social media and both the interaction level on social media and the participant's resulting emotional response to using social media. This is to be expected; if a person spends more time on social media, they are more likely to be interactive on the sites. The amount of interaction on social media was strongly correlated with the participant's emotional response to social media use. These findings cause us to believe there may also be a reciprocal relationship between the amount of time a participant devotes to social media, the amount of interaction on these sites, and the emotional response social media invokes. In essence, the more time a participant devotes to social media, the more likely they are to interact on these sites, and the likelihood of social media invoking a positive emotional response increases. This increase in emotional response causes the participant to devote more time on social media.

This reciprocal relationship is supported by information gained during participant follow up interviews. One participant stated:

> I think [the groups are] completely helpful, but you get out of it what you put in. I feel it's really important to be an active member in social media groups because you're able to build strong bonds and connections with other CF'ers.

The most common theme that emerged during these interviews was the exchange of support on social media sites related to CF. This theme consisted of both providing support for others and receiving support themselves. As one woman shared, "I have found that through social media I have been able to connect with and what I call virtually

meet each other and form friendships. Real, honest caring friendships I never would have been able to without these sites."

2.5.2 Emotional Well-Being of Participants The HRQoL measurement for CF patients has been used through a validated questionnaire, the Cystic Fibrosis Quality of Life (CFQoL) questionnaire (A. L. Quittner et al., 2000). Based on previous studies using the CFQoL, we were able to calculate a treatment burden, emotional well-being, and social-well-being score for participants to assess their emotional well-being (A. L. Quittner et al., 2000; A. L. Quittner et al., 2005). Participant emotional well-being, social well-being, and treatment burden scores were found to be strongly correlated with one another. This is to be expected, as individuals who have a higher emotional well-being are likely to be more social, and therefore have a higher social well-being. Individuals with a lower treatment burden are likely to be more emotionally and socially adjusted and therefore have a higher emotional and social well-being. Overall, individuals with higher scores in all three categories are likely to have a higher HRQoL.

Multiple participant demographics related to participant physical health had an impact on participant well-being scores. Participant age was negatively correlated with participant social well-being score. This can be interpreted that individuals with CF who are of an older age are less socially active. Previous studies have found a negative correlation between age and social well-being score as well as age and emotional well-being score (A. L. Quittner et al., 2005). We could posit that the use of social media for support might have a positive impact on the participant's emotional well-being score. Therefore, our participant population may have a higher score emotional well-being score compared to individuals who are not using support groups related to their CF.

Participant FEV_1 percent of predicted was negatively correlated with participant age. This was to be expected, because over time, FEV_1 declines because of damage from lung disease and exacerbations ("2012 Annual Patient Report," 2013). Participant FEV_1 also had a statistically significant correlated with participant social-well-being and patient treatment burden. This can be interpreted that participants with a lower FEV_1 have a less active social life. Participants with a lower FEV_1 score also feel that their treatments are more burdensome on a day-to-day basis. Similar findings from previous study using the CFQoL and FEV_1 percent of predicted (to evaluate physical health) found that patients with good lung function reported better physical HRQoL than those with poor lung function (Riekert et al., 2007). Worsening disease severity, along with challenges to daily self-management, may impact the health-related quality of life of adults with CF (Sawicki et al., 2011). However, during the development of the CFQoL, an individual's FEV_1 was found to be correlated with patient emotional well-being and social well-being, but was not found to be correlated with treatment burden (A. L. Quittner et al., 2005).

2.5.3 Impact of Patient Demographics on Social Media Use Similar to previous studies, the majority of our participants were Caucasian females (Edwardsen et al., 2013; Shaw & Johnson, 2011; Shpigelman & Gill, 2014). However, we determined that gender had no statistical impact on if the participant used social media, how often they used social media, whether the participant interacted with other users through social media, how often they interacted with others on social media, and the patient's emotional response while using social media. These quantitative results were surprising, considering other studies had found gender differences between individuals who used social media for support purposes (Seale et al., 2006; van Uden-Kraan et al., 2009).

Previous studies have found that men are more likely to claim to use the Internet to seek information and women are more likely to say that they seek social support (Seale et al., 2006). Through qualitative analysis, we found that female participants were more likely to mention a need for support compared to male participants, although both men and women mentioned feelings of isolation due to CF. However, one man stated the following: "The very first person I met with cystic fibrosis I call her my little cystic fibrosis angel and [her support] was pretty positive."

We hypothesize that although men and women both use social media for support related purposes, the majority of individuals on CF-related social media sites are female. This can be attributed to the female gender, which, according to the World Health Organization, has a higher incidence of depression compared to males (WHO, 2014). This gender difference may also be due to the "CF-gender gap," where females with CF have lower rates of mortality and survival compared to males with CF (Sweezey & Ratjen, 2014). Women with CF tend to have poorer health, which we hypothesize may cause women to be the predominate users of social media for support purposes.

There was also no statistically significant impact of ethnicity on social media use, although this may be skewed due to vast amount of Caucasian participants in this study (97%). Previous studies have found that African American adults are the most active users of the mobile web (Lenhart, Purcell, Smith, & Zickuhr, 2010). Our study had no African American or Hispanic participants. This skewed participant ethnicity is likely due to the low incidence of CF in individuals with African American (1 in 15,000 births) or Hispanic (1 in 13,000 births) ethnicity compared to individuals with Caucasian ethnicity (1 in 2,500 births) ("State of Lung Disease in Diverse Communities," 2010).

The majority of our participants were between 18-32 years old, which we found to be similar to previous studies of social media users (Shpigelman & Gill, 2014). Social media use is generally highest in individuals aged 12 to 29 with approximately 73% of teens and young adults in this age group participating in social networking sites as compared to only 39% of individuals over the age of thirty (Lenhart et al., 2010). However, we found that there was no statistically significant relationship between participant age and their use of social media, how often they used social media, whether the participant interacted with other users through social media, how often they interacted with others on social media, and the patient's emotional response while using social media.

Our patient demographics regarding marital status, education level, and work status were comparable to the 2012 CF Foundation Patient Registry ("2012 Annual Patient Report," 2013). Marital status, education level, and work status did not have a statistically significant impact on social media use, the amount of time they spend on social media, whether they interact on social media, the amount of time they interacting on social media, or their emotional response to social media. However, work status did have an influence on the participant's social media usage score, although the relationship was not statistically significant. According to our data, 37% of participants in this study reported they were unable to attend school or work due to their health, compared to 17% of patients who reported disabled status according to the CF Foundation patient registry ("2012 Annual Patient Report," 2013). It is reasonable to hypothesize that individuals who are disabled due to their health may use social media more frequently.

2.5.4 Impact of Treatment Burden on Social Media Use One objective of our study was to determine if participant's physical and emotional well-being related to CF impacts their use of social media. We found that physical symptoms and perceived treatment burden have a significant impact on the participant's use of social media. "Treatment burden, both objective and perceived, in a chronic disease such as CF is a function of several factors, including the number of therapies required on a daily basis, the frequency of such therapies, the complexity of administering therapies, and the amount of time needed to complete a therapy" (Sawicki, Sellers, & Robinson, 2009). We hypothesize that the more significant the participant perceives their symptoms to be, the more likely they are to use social media. Patterson et. al, 2001 hypothesized that patients have shifting perspectives on their illness, meaning persons with chronic illness sometimes have illness in their psychological foreground and sometimes wellness (Patterson, 2001). If the individual with CF has more physical symptoms and treatments, their disease is on their psychological "foreground," which triggers a desire for emotional support from others with the same concerns. Previous studies have found that worsening disease severity, along with challenges to daily self-management, may impact the health-related quality of life of adults with CF (Sawicki et al., 2011). Adults may find their disease management becomes onerous over time and due to the requirements of treatments, it can become increasingly difficult to fulfill their aspirations for a "normal" life. (Badlan, 2006).

We found that participant treatment burden score, or the amount of perceived burden of treatments on the participant's daily life, strongly influenced if an individual was a "poster or a lurker" on social media. Treatment burden was strongly negatively

correlated with the amount of time participants spent on social media and the amount of participant interaction on social media sites. Participant treatment burden was negatively correlated with the participant's emotional response to social media, although this relationship was not statistically significant. Adults with CF may require daily treatments of: use of PERT, monitoring of caloric intake, monitoring blood sugars, ACTs, inhaled bronchodilators, inhaled antibiotics, inhaled mucolytics, and anti-inflammatory therapies (Sawicki et al., 2011).

The amount of participant hospitalizations in the past year was also negatively correlated with both participant emotional well-being score and treatment burden score. This could be interpreted that as participant hospitalizations increase, their emotional well-being is affected. Conversely, patients who feel their treatment is a larger burden (and may not do treatments as often) could have more hospitalizations.

The amount of time the participant spent on chest therapy influenced if the participant used social media for support related to their CF, strongly influenced if the participant was a poster or lurker on social media sites, and was correlated with the amount of time the participants spent on social media, the amount of interaction participants experienced on social media, and the participant's emotional response to social media. Lung transplant status was found to be associated with participant's poster or lurker status. Participant status for the bacteria *P. aeruginosa* influenced the amount of participant interaction on social media sites. Patients infected with *P. aeruginosa* have been found to score more poorly in domains assessing physical wellbeing (treatment burden) due to increased therapy for symptoms related to their infection and also in domains assessing psychological functioning (emotional well-being) (Ashish, Shaw,

McShane, Ledson, & Walshaw, 2012). This lower physical and psychological functioning may increase the participant's need for support and promote the desire to interact on social media sites.

PEI, which results from intestinal malabsorption, was found to be associated with participant's use of social media and the patient's poster vs. lurker status. PEI requires individuals to use PERT and may cause individuals to have significant weight loss due to inadequate caloric intake. If the weight loss is significant, patients may be required to receive a GT for supplemental feedings (Ramsey et al., 1992). If a patient receives a GT, this can cause significant lifestyle changes, which can cause CF to be on the patient's psychological foreground.

Previous studies have found that CF patients can feel a sense of being an "imposter" in the normal world due to their frequent treatments and their CF symptoms (Badlan, 2006). Adults with CF can have difficulties in developing interpersonal relationships, and as a result, be left isolated and socially maladjusted (Pfeffer et al., 2003). During follow-up interviews, one major theme that occurred were feelings of isolation due to CF. As one woman stated:

> My medical group knows everything about it but they can't actually know what it feels like…other people with CF on the group know exactly how it feels to have a problem. Coughing up blood and going to the hospital, not being able to breathe. Someone else knows exactly what you're going through. And how every single day you're fighting this disease. You never get a break.

The theme of isolation due to CF was also found in a previous qualitative study about the use of the Internet by individuals with CF to exchange information. This study by Pimentel, et. al found that, "Seeing themselves in others cemented the feelings of friendship and partnership. Perceiving oneself as a normal person when meeting so many people with the same problem in the virtual space makes the rarity condition of the disease less significant" (Pimentel et al., 2013). Our study found that increased symptoms, therapies/treatments, and treatment burden perception of participants impacts the use of social media for support related to their CF.

2.5.5 Use of Social Media for Health-Related Information The use of social media to obtain health-related information was a common theme throughout our study. Patients may use social networks to: exchange information on subjects such as the experience of bodily symptoms, clinical diagnosis and treatment options, adverse treatment effects, sources of medical evidence, experiences with individual providers and opinions about their quality (Griffiths et al., 2012). Many participants used social media to ask others with CF about their own personal experiences with medications, testing, or milestones in their lives (such as having children). This correlates with previous studies, which have found that a majority of their participants with a chronic health condition seek online health information (Pimentel et al., 2013; Shaw & Johnson, 2011; van Uden-Kraan et al., 2009). In the previous study by Pimentel et. al, participants accessed and searched for health information related to their CF at the beginning of their diagnosis, with Internet searches becoming less frequent over time. This conflicts with our data, in which almost 60% of participants were diagnosed at birth or less than one year old and were still using social media for support related to their CF. Participants in our study

continued to access health information as they aged and encountered difficulties in their lives. As one woman stated, "We encounter health problems along the way and just to see how [others with CF] cope with these problems has been really encouraging." Similar to previous studies, participants became more optimistic about their own future by reading the disease stories of other participants who served as role models (van Uden-Kraan et al., 2009).

As with other studies, a limitation of exchanging information via social media is that the information is usually based on personal experience rather than factual medical information (Mo & Coulson, 2013; Pimentel et al., 2013; van Uden-Kraan et al., 2009). While exchanging medical experiences via online support groups is beneficial, we suggest that social media users still verify any medical information collected through social media sites with their medical team.

2.5.6 Negative Experiences Using Social Media In addition to the positive experiences many participants shared during our study, there are multiple drawbacks that individuals with CF should be made aware of prior to using social media. One drawback is the increased possibility of offensive or antisocial behavior (Lee, 1996). This may be due to anonymity, lack of real-time responses, and lack of social status cues that normally inhibit inappropriate responses (Braithwaite et al., 1999). Participants shared similar experiences to previous studies. Multiple individuals described "Internet trolls," which was described by a participant as, "Someone who instigates trouble in a group." Another participant described a troll as, "[Someone who] intercedes with people's questions and correspondences in a negative way." It is a common concern of social media users that

the people they are interacting with online may not be honest about their identity, motivations, or experiences (Mo & Coulson, 2013).

Another potential drawback of using social media is the possibility of being confronted with a "vision of the future" (Plumridge et al., 2012). One participant shared:

> I used to go on support groups way more often, at least once a day for an hour at least. I made many friends and about 80% of them have passed away because of CF. This got too depressing for me, so I seriously cut back on the number of and time I spend on support groups for CF…[Support groups] make you feel like you're not alone, yes, but you are not alone in a very dark place.

Previous studies have found that the unpredictable nature of CF, the suffering that young adults believe they would have to endure, and premature death due to ill health may be a concern for young adults (Higham et al., 2013). Being faced with the declining health of others with the same chronic condition can remind individuals of the terminal nature of CF. However, this phenomenon can also be experienced through in-person support groups for individuals with chronic conditions.

2.5.7 Limitations and Future Research As with any Internet based research, the self-selected sample, unknown response rates, and lack of control over who accesses the survey are limitations of the current study (Shpigelman & Gill, 2014). The individuals who participated in our study were most likely the most active members of their support group. Participants for these surveys were contacted and asked to participant through a limited number of social media venues which may have biased the results of participant use of social media and which social media venues were most favorable. Although we

had 121 participants, we had a rather homogenous participant group. The majority of our sample was comprised of Caucasian adult females with CF. Variations in gender and ethnicity may have proven a broader understanding of the use of social media as a support network for other conditions. Another limitation that should be taken into account is this was a retrospective study. Because patients use online support groups over long periods of time, the outcomes they report retrospectively may be underestimated because their impact was gradual or they were overestimated in order to justify their extended use.

Future research that could allow for a more heterogeneous participant group would allow for more of an unbiased sampling. This could be done through distributing the survey through a national organization (like CF Foundation) or through multiple CF clinics in different demographic locations. Future research could also focus on the use of social media for support by children and young adults with CF. This is especially important as patients begin to transition from pediatric to adult healthcare settings. In addition, future research could focus on suggestions from participants about how healthcare providers like genetic counselors can suggest online support groups to their patients. Finally, future research could focus on participants with other chronic genetic conditions, such as chromosomal conditions, which have a lower population incidence and have a less established natural history of the condition compared to CF.

2.6 Conclusion

This study focused on determining if individuals with CF use online social media for support related to their condition, how often they use social media related to support, which social media sites they use, and their thoughts on social media use. We also

correlated participant's use of social media to their physical and emotional well-being. Overall, participants who used social media more often and interacted more on these sites had a strong positive emotional response as a result of using these sites. The majority of participants were actively posting on these sites and interacting with other users, which we theorize is due to the chronic nature of CF. Individuals who post on these sites have a stronger emotional response and feel a stronger sense of support compared to individuals who just read these social media sites.

Based on their responses, participants used social media both for emotional support and information gathering purposes due to feelings of isolation as a result of their CF. Caucasian females were the most frequent users of social media sites for CF-related support in this study, which may be due to the "CF gender bias," where females tend to have more severe symptoms compared to males. Participants who were more likely to use these sites reported a higher treatment burden and more symptoms related to CF, which puts their CF on their "psychological foreground" on a daily basis. These individuals then use social media more often and are more likely to interact on these sites to receive support.

We believe that healthcare professionals should consider suggesting social media to individuals with CF as a resource for emotional support or even utilizing social media as a CF center approach to promoting psychological well-being, so long as they also brief their patients with CF on the potential drawbacks as well. Our study shows that using social media for CF-related support purposes is beneficial to individuals with CF and users who interact frequently on these sites have a positive emotional response.

Chapter 3: Conclusions

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Appendix A. Request to Post Survey

Dear (name),

My name is Margo Faust and I am currently a genetic counseling graduate student at the University of South Carolina School of Medicine in the United States. As a part of my Masters' thesis, I am conducting research on the use of social media by adults with cystic fibrosis as a support network.

I am very interested in gathering information about the use of social media as a support network from the members of your online community. I am writing to ask if you would consider posting a link to my survey on your (website/blog/forum) (and if you would consider taking my survey yourself!). I have attached a copy of sample post (Appendix C), which includes all the information about my research and a link to the survey that you would be able to post.
I would greatly appreciate the opportunity to ask your community to participate in this survey.

If you have any additional questions, please feel free to contact me or my thesis advisor.

Thank you,

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Appendix B. List of Social Media Sites Where Survey Links Were Posted

Facebook Groups:
Cystic Fibrosis Support Group: https://www.facebook.com/groups/380217821994668/
Cystic Fibrosis Support group: https://www.facebook.com/groups/212500738842774/
FUN CFers UNITE !!: https://www.facebook.com/groups/220203011360638/
TX Cystic Fibrosis Group: https://www.facebook.com/groups/425839890772265/
CF Society: https://www.facebook.com/groups/CFSocietyOrg/
Cystic Fibrosis Fighters: https://www.facebook.com/groups/410003055781521/
Cystic Fibrosis: https://www.facebook.com/groups/281276421924031/
Cystic Fibrosis: https://www.facebook.com/groups/cysticfibrosiskhi/
Faces of Cystic Fibrosis: https://www.facebook.com/groups/476913345678336/
CF Connect: https://www.facebook.com/groups/cfconnect/
Our CF family: https://www.facebook.com/groups/193696120673540/
Cystic Fibrosis Divas n Dudes:
https://www.facebook.com/groups/CysticFibrosisDivasnDudes/
Cystic Fibrosis: https://www.facebook.com/groups/2207539081/
CFRD Cystic Fibrosis Related Diabetes:
https://www.facebook.com/groups/322442614556293/
Cystic Fibrosis Research News: https://www.facebook.com/groups/260687967322126/
Cystic Fibrosis Support Network of Michigan:
https://www.facebook.com/groups/CFSNofMichigan/
Cystic Fibrosis QLD: https://www.facebook.com/groups/375055955846201/
Cystic Fibrosis United: https://www.facebook.com/groups/312646568835014/
Positively Cf: https://www.facebook.com/groups/471565866253359/
CF Gang (Cystic Fibrosis):
https://www.facebook.com/groups/cysticfibrosissupportgroup/
Arkansas Cystic Fibrosis Connection:
https://www.facebook.com/groups/489665034424033/
Cystic Fibrosis Canada- Kitchener-Waterloo & District chapter:
https://www.facebook.com/groups/kwdcfc/
Cystic Fibrosis: https://www.facebook.com/groups/123016281174596/
Cystic Fibrosis Singles: https://www.facebook.com/groups/427341737317940/
I Have Cystic Fibrosis and/or Bronchiectasis and Im Still Smiling =):
Cystic Fibrosis Disability CF SSI SSA SSDI:
https://www.facebook.com/groups/237267918278/
CFCF- Cystic Fibrosis Christ Followers:
https://www.facebook.com/groups/547643845277721/
Cystic Fibrosis understanding the struggles and fights of our CF loved ones:
https://www.facebook.com/groups/1381766768707705/
CF Mamas: https://www.facebook.com/groups/Cfmamas/

Cystic Fibrosis: https://www.facebook.com/groups/439979999432493/
CYSTIC FIBROSIS: https://www.facebook.com/groups/425039967569908/
Cystic Fibrosis Community Support Forum:
https://www.facebook.com/groups/489815157767385/
Cystic Fibrosis Support & Advice Group- Australia:
https://www.facebook.com/groups/185253548210002/

Blogs:
CF Blogroll: http://cfblogroll.blogspot.com/
Cheriz's CF Blog: www.cheriz.org

Appendix C. Invitational Letter to Participate in Survey

Hello,

My name is Margo Faust and I am currently a second year student in the genetic counseling program at the University of South Carolina School of Medicine.

As a part of my Masters' thesis, I am conducting research on the use of social media by adults with cystic fibrosis as a support network.

Like many of you, I use social media in my everyday life and find it to be an integral part of the online community today. I am interested in seeing how adults with CF such as you use social media to gather information and support about CF.

I would like to invite you to participate in an online survey about your use of social media. This survey should take around 10-15 minutes to complete. At the end of the survey, you will be given the option to provide your contact information for a follow-up phone interview at your convenience. I would love the opportunity to talk with you briefly about the specific ways in which you find social media helpful in your day-to-day life.

To complete this survey please click the link below:

http://www.surveymonkey.com/s/CFsocialmediasurvey

Thank you for your time and consideration to participate in this survey. Your responses may help genetic counselors understand if adult CF patients seek emotional support and what online sites patients use. If you have any questions regarding this research, you may contact either myself or my faculty advisor, Andrea Sellers, MS, CGC, using the contact information below.

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Faculty Advisor
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Appendix D. Online Survey

Qualifying Demographics:

1. What is your age?

Under 18 or 18-100
(Note: Individual ages are listed for participants to choose from)

2. Do you have cystic fibrosis? Yes/No

(Note: These are exclusionary questions, if the participant answers they are under 18 or do not have cystic fibrosis, they are sent to a disqualification page.)

Section 1. Please answer this group of questions so that we know some facts about who you are:

What is your gender?
Male
Female

What is your current marital status?

Single/never married
In a relationship
Married
Widowed
Divorced
Separated
With a partner

Which of the following best describes your ethnic background?

Caucasian
African American
Hispanic
Asian/Oriental or Pacific Islander
Native American or Native Alaskan
Prefer not to answer this question

What is your highest level of schooling?

Did not attend school

Did not finish high school
Completed high school or GED
Some college education
Associate's Degree
Bachelor's Degree
Graduate School

Which of the following best describes your current work or school status?
Attending school outside the home
Taking educational courses at home or online
Seeking work
Working full or part time (either outside the home or at a home-based business)
Full time homemaker
Not attending school or working due to my health
Not working for other reasons

Section 2. Please answer this group of questions so we can have an accurate measurement of your current physical health.

At what age were you diagnosed with CF?
At birth
Less than 1 years old
(Options 1-100)

What is your most recent FEV_1% (Forced Expiration Volume) measurement (aka Percent Predicted)?
When was the last time this was measured?

Have you received a lung transplant?
Yes
No

Are you pancreatic insufficient (Do you take pancreatic enzymes)?
Yes
No

Have you ever tested positive for the bacterial infection, *Burkholderia cepacia (B. cepacia)?*
Yes
No
Have you ever tested positive for the bacterial infection, *Pseudomonas aeruginosa* (*P. aeruginosa)*?
Yes
No

What type of therapy do you use? (Please check all that apply)

Coughing
Chest Physical Therapy
Oscillating Positive Expiratory Pressure device (ex. Flutter, Acapella, Cornet)
"Vest" therapy
Autogenic drainage
Breathing techniques
Cardio exercise
Other, please describe

How often do you perform "chest therapy?"
Weekly
2-3 times per week
Once a day
Twice a day
Only when sick or in the hospital
I do not perform chest therapy

How often were you hospitalized in the past year?
I have not been hospitalized in the past year
Once
Twice
Three times
Four times
More than 5 times

Section 3. Social media related questions: Please answer these questions to describe how often you use social media for support related to CF.

Do you use online support groups and social media sites dedicated to individuals with cystic fibrosis for any reason (ex. Blogs related to CF, facebook groups related to CF, twitter related to CF, online support groups related to CF)?
Yes
No

(If no, will skip to health questions)

If yes, how much time do you spend on online support groups or social media specifically for CF per week?
Less than 2 Hours
2-7 Hours
8-15 Hours
15-20 Hours
More than 20 hours

Generally, how much time do you spend on all online support groups or social media per

week (CF related and non-CF related)?
Less than 2 Hours
2-7 Hours
8-15 Hours
15-20 Hours
More than 20 hours

How often do you get online at various social media sites to access information, news, or support for CF?
A few times per month
Weekly
Two to three times per week
Daily
Twice or more a day

What type of online support groups do you use related to CF? (Please check all that apply)
Facebook groups
Myspace
Twitter
Google+
Youtube
Blogs
Online support groups (ex. CysticLife, Cysticvoices, or similar)
Online chat rooms
Other (please list) _____

Do you interact with other CF patients on these sites?
Yes, I post on these sites.
No, I just read these sites.

Please describe how often other users: (Options: 'seldom to never'; 'sometimes'; 'regularly'; 'often'.)

1. Members of these sites start a private conversation with me.
2. Members of these sites reassure me.
3. Members of these sites offer me advice.
4. Members of these sites confide in me.
5. Members of these sites ask me for my help or advice.
6. When I use these sites, I experience the sense of 'not being the only one."
7. When I use these sites, I experience the feeling that I am not so bad off after all.
8. When I use these sites, I feel that I can share my experiences with my illness with others.

Please agree or disagree with each statement: ('completely disagree'; 'disagree'; 'neither agree nor disagree'; 'agree'; 'completely agree'.)

1. Since I began to use these sites, I feel that I am more knowledgeable about which questions to ask my healthcare providers
2. Since I began to use these sites, I feel that I am more open about my cystic fibrosis with others
3. Since I began to use these sites, I feel I am more capable at emotionally coping with my CF
4. Since I began to use these sites, I feel more emotionally in control over my CF
5. Since I began to use these sites, I have less faith in the future.
6. Since I began to use these sites, I feel more positive about my life with CF.
7. Since I began to use these sites, I have more faith in the future.
8. Since I began to use these sites, I feel less emotionally in control over my CF
9. Since I began to use these sites, I have a greater sense of worth.
10. Since I began to use these sites, I feel less lonely.
11. Since I began to use these sites, I have made new social contacts.

What other comments would you like to make about using social media that is specific for young adult who have CF?

Section 4.

CF related questions: Please answer these questions to describe how you feel about your CF during your day to day life.

***During the past two weeks**, indicate how often:*

Always
Often
Sometimes
Never

1.I felt worried
2. You felt useless
3.You felt sad

*Thinking about your health during the past **two weeks**, indicate the extent to which each sentence is true or false for you.*

Very true
Somewhat true
Somewhat false
Very false

1. I often feel lonely
2. It is difficult to make plans for the future (for example, going to college, getting married, advancing in a job, etc.)
3. I have to stay at home more than I want to
4. I feel comfortable discussing my illness with others

5. People are afraid that I may be contagious
6. I get together with my friends a lot
7. I think my coughing bothers others
8. I feel comfortable going out at night

To what extent do your treatments make your daily life more difficult?
1. Not at all 2. A little 3. Moderately 4. A lot

How much time do you currently spend each day on your treatments?
1. A lot 2. Some 3. A little 4. Not very much

How difficult is it for you to do your treatments (including medications) each day?
1. Not at all 2. A little 3. Moderately 4. Very

Section 5. Follow-Up Interview Invitation

Would you be interested in participating in a 10-15 minute telephone interview to discuss your experiences with social media as a support network in further detail?
Yes
No

If No: Thank you for your time and participation in this research study.

If Yes:

Please fill out your contact information below. This information will remain private and be used only for the purpose of contacting you for participation in this research study.
Name:
Phone Number:
Best time to contact you at the phone number provided:
Morning (10am-12pm)
Afternoon (1pm-5pm)
Evening (6pm-8pm)
Weekend

Email (optional):

Thank you for your time and participation in this research study.

Appendix E. Questions Extracted From CFQ-R

Please answer these questions to describe how you feel about your CF during your day to day life.

***During the past two weeks**, indicate how often:*

Always
Often
Sometimes
Never

1. I felt worried
2. You felt useless
3. You felt sad

*Thinking about your health during the past **two weeks**, indicate the extent to which each sentence is true or false for you.*

Very true
Somewhat true
Somewhat false
Very false

1. I often feel lonely
2. It is difficult to make plans for the future (for example, going to college, getting married, advancing in a job, etc.)
3. I have to stay at home more than I want to
4. I feel comfortable discussing my illness with others
5. People are afraid that I may be contagious
6. I get together with my friends a lot
7. I think my coughing bothers others
8. I feel comfortable going out at night

To what extent do your treatments make your daily life more difficult?
1. Not at all 2. A little 3. Moderately 4. A lot

How much time do you currently spend each day on your treatments?
1. A lot 2. Some 3. A little 4. Not very much

How difficult is it for you to do your treatments (including medications) each day?
1. Not at all 2. A little 3. Moderately 4. Very

Appendix F. Follow Up Phone Interview Questions

Hello, may I please speak with Mr./Ms. _____

My name is Margo Faust and I am a genetic counseling student at the University of South Carolina School of Medicine. I am calling you in regards to an online survey you recently filled out about your use of social media as a support network for your CF. Is this a convenient time for me to speak with you?

As you may remember from filling out the survey, I am interested in understanding what types of online support groups are being used by individuals with CF and how social media is being used as a support network. I will be asking you a series of questions about your use of social media for support in order to gain a more detailed understanding of your reasons for using and what you gain from using social media as a support network for CF. This interview should take about 15-20 minutes of your time.

This interview will be recorded and transcribed for the purpose of the research study. All of the information gathered from this study will remain confidential and your contact information will be discarded upon completion of this interview.

Please feel free to ask me any questions you may have or express any concerns you may have during our conversation. Your participation in this phone interview is completely voluntary and you may stop the interview at any time. If you are uncomfortable with any of the questions I am asking or do not wish to respond, please feel free to let me know and I will move on to the next question.

Do you have any questions before we begin?

Phone Interview Questions

1) Do you use social media for CF-related support?
2) If yes, how often do you use these social media sites?
   (If you do not use them, why not? Have you tried to use these social media sites before?)
3) Which social media sites do you use? Why do you choose these specific sites?
4) In general, what motivates you to log onto these sites? (For example, prior to a doctor's appointment, after a doctor's appointment, after a hospitalization, etc.)
5) Have you had any positive experiences on these social media sites? Please give an example.
6) Have you had any negative experiences on these social media sites? Please give an example.
7) How do you feel when you use these sites for support related to CF?

8) What support related to your CF do you utilize besides these social media sites? (Family, friends without CF, clinic)
9) Do you recommend other adults with CF to use social media sites for support related to their CF?

Mr./Ms. _____ , I would like to thank your time and participation in this research study. Your answers to these questions will provide us with better insight into social media use in the CF community and how we as healthcare professionals can inform our patients of social media support.

Do you have any questions for me? Thank you again for your time and participation and have a wonderful day/evening.