THE ROLE OF SOCIAL MEDIA IN THE RELATIONSHIP BETWEEN SOCIAL SUPPORT AND ADHERENCE IN CHILDREN WITH CYSTIC FIBROSIS

A dissertation submitted to
Kent State University in partial fulfillment of the requirements for the degree of Doctor of Philosophy

by

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August 2016

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ACKNOWLEDGEMENTS

I would like to say a sincere thank you to my graduate advisor, Dr. Beth Wildman. I am truly indebted to you for your continued support and guidance throughout my graduate career. You encourage your students to follow their own path with both their research and clinical interests, while providing invaluable guidance and support along the way. I would also like to thank my committee members, Drs. Masterson, Merriman, Roxburgh, and Claassen for their time and guidance on this study.

Words can’t fully describe how thankful I am to the following family members. To my Auntie and godmother Gloria Vargay, thank you for keeping me in your thoughts and prayers always. You have been the perfect example as a godmother; your kindness, sweet nature, and dedication to your church and family is remarkable. To my cousins, Lori Bray and Joseph Vargay, thank you for being my first and forever friends in this world. You are an inseparable part of my story and I am so grateful for the memories we shared. To my uncle Joseph Vargay, thank you for always being my “Mr. Fix It,” and coming to my aid whenever I call. To my uncle and godfather Mark Babyar, thank you for being my “technological benefactor” and supplying me with electronics throughout graduate school. You have been the true definition of “cool Uncle,” always excited to go on an adventure with me. To my little sister, Maurie Babyar, thank you for being a gift of joy and unwavering support in my life. “Big sister” was not a title I took lightly, I wanted to set a good example and make you proud, in many respects this accomplishment is yours. To my mom and dad, Michael and Janice Babyar, there is no way I could ever put into words the amount of thanks you are owed. Thank you for always putting me
first, for loving me more than you love yourselves, for giving me a beautiful home to grow up in, and for encouraging me to love learning and exploring by taking me to museums and new cities.

To my husband, Michael Rakestraw, thank you for being you, my perfect match in every way. I met my soul mate, in every sense of the word. I am looking forward to the next phase of our adventure together, and I am truly grateful for every day with you.

I would like to say a very special thank you to my church family, the members of St. Stephen’s Evangelical Lutheran Church. Being greeted by your smiling faces and hugs every Sunday has meant so much to me. Finally, this dissertation is in memory of my grandparents, Eleanor “Mocky” and Michael Babyar, and Gloria Ocenas. It is a privilege and an honor to be your granddaughter.
CHAPTER I

INTRODUCTION

Individuals with CF adhere to their medical treatment by following standard medical treatment regimens prescribed by their doctors. Standard medical treatment regimens can vary but can potentially include oral antibiotics, inhalers, aerosol medications, breathing treatments, vitamins, nutritional supplements, and pancreatic enzymes to aid with digestion (Modi et al., 2006). Also, individuals with CF are a unique patient population, as they are at increased risk of transmitting and acquiring patient-to-patient lung pathogens (Saiman et al., 2014). Therefore, the minimization of infection is critical to the immediate and long-term survival of CF patients. Evidence-based infection control (IC) guidelines have been implemented for the CF community to lessen the frequency of infection transmission to CF patients; highlighting the minimization of person-to-person contact between individuals with CF (Saiman et al., 2014). Study findings suggest participating in an intervention specifically with peers with the same medical condition can improve children’s health behaviors. However, in the case of Infection Control, social contact between CF patients is discouraged (Saiman & Siegel, 2004). Thus, elimination of group-based activities and minimizing contact between patients has led to a loss of peer support (Russo, Donnelly, & Reid, 2006). Although person-to-person contact between CF patients is discouraged, the World Wide Web represents a relatively new source of health information and support available online. With this increased access to social networking sites, it is possible for young people with CF to seek out social support online as person-to-person contact is discouraged. The present study aims to examine the social network use of adolescent and young
adults with CF regarding social support and explore how social network experiences/exposure affects health related behaviors.

**Cystic Fibrosis: An Overview**

Cystic fibrosis (CF) is a genetic, chronic disease directly related to dysfunctional chloride transport throughout the body (Boucher, 2002). A defective gene is implicated in CF that causes abnormally thick sticky mucus, which ultimately obstructs the airway leading to the lungs, and increases pathogen colonization in these individuals (Chiarini et al., 2010; Paroni et al., 2013). Potentially dire complications arising from these defects include premature death, which makes adherence to treatment regimens a vital factor in the successful management of the disease. Such treatment regimens have prolonged the life span of CF patients, with advances in early diagnosis, care, and disease therapy (Aurora, et al., 2011; Simmonds, 2013). Consequently, the actual effectiveness of medical treatments can vary greatly depending on how closely treatment protocols are followed. The practice of following prescribed medical treatments has been identified as treatment adherence, and defined by Haynes (1979) as, “The extent to which a person’s health behaviors (e.g., medication use, following diets, and/or exerting other lifestyle changes) coincide with recommendations given by health professionals.” While it may be intuitive that an individual would always want to adhere to their treatment regimens, a substantial number of patients with a chronic illness (i.e., as many as 25%–50%) are nonadherent to one or more recommendations provided as part of their medical treatment regimen (Dunbar-Jacob & Mortimer-Stephens, 2001; La Greca & Bearman, 2003; Rapoff, 2009). The negative consequences of nonadherence are dire, and can include increased morbidity, higher rates of mortality, medical complications, symptom exacerbation, and increased school/occupational absence (Dasenbrook, et al., 2010; Leung & Olivier, 2013; Sanders, Bittner, Rosenfeld, Redding,
Moreover, nonadherence to medical treatment regimens is also related to escalated rates of health care utilization (e.g., physician visits and hospitalizations), resulting in significant financial consequences (Iuga & McGuire, 2014). An estimate of health care dollars misallocated due to poor adherence to medical regimens in chronic illness populations is approximately 300 billion dollars annually (Berwick & Hackbarth, 2012; DiMatteo, 2004). Thus, this area of research is not only of importance for individuals with a chronic illness and their families, but for society as a whole.

**Infection Control Adherence**

Individuals with CF are a unique patient population, as they are at increased risk of transmitting and acquiring patient-to-patient lung pathogens. Chronic lung infections have been linked to significant lung disease and damage, morbidity, and mortality in individuals with CF (Aaron et al., 2010; Savant, O'Malley, Bichl, & McColley, 2014; Vanderhelst et al., 2011). Although the life expectancy of individuals with CF has steadily increased because of improvements in treatment, bacterial lung infection remains a large threat (Dasenbrook et al., 2010). Approximately 90% of CF related deaths are due to respiratory failure caused by chronic lung infection (Cystic Fibrosis Foundation, 2003). Pathogens that commonly infect the lungs of patients with CF include Staphylococcus aureus, Haemophilus influenzae, Pseudomonas aeruginosa, and Burkholderia cepacia (Saiman et al., 2014). Aggressively treating pulmonary infections with antibiotics has contributed to improved survival in patients with CF but has also promoted multiple-drug-resistant bacteria (Saiman et al., 2014). Therefore, the minimization of infection is critical to the immediate and long-term survival of CF patients.

Evidence of patient-to-patient transmission of pathogens and the increasing complexity of CF care pointed to the need for greater awareness and implementation of infection-prevention
and control practices by both patients and clinicians (Saiman & Siegel, 2004). In 2013, the Cystic Fibrosis Foundation (CFF) reconvened a committee to update evidence-based infection control (IC) guidelines for the CF community to lessen the frequency of infection transmission to CF patients (Saiman et al., 2014). Among the IC recommendations issued by the CFF, transmission-based precautions highlight the minimization of person-to-person contact between individuals with CF (Saiman et al., 2014). This is because CF patients potentially harbor clinically important microorganisms, even if they have not yet been detected in cultures from the respiratory tract. Such secretions can transmit infectious agents to other CF patients (Saiman et al., 2014). Therefore, transmission-based IC precautions are of particular interest due to implementation difficulties/burden and potential negative social consequences associated with isolating CF patients from one another (Miroballi et al., 2012). While the medical basis for adherence to IC recommendations is clear, there is limited research on the psychosocial impact of IC recommendations (Saiman et al., 2014).

Few studies examining the psychosocial implications and patient and family perceptions of IC guidelines have been conducted. Previous research has demonstrated that patients and families may not believe they are susceptible to infection via direct contact with other CF patients (Masterson, Wildman, Newberry, Omlor, Bryson, & Kukay, 2008). Moreover, a high proportion (70%) of participants in the same study felt that they would uniquely benefit from friendships with fellow CF patients (Masterson et al., 2008). These data suggest that, if given the opportunity, individuals with CF are at risk for initiating or maintaining contact with other CF patients. In a similar study, patients reported the reasons for their ambivalence or disapproval with IC guidelines included: social and emotional concerns related to not socializing with other CF patients, inconclusive evidence regarding person-to-person transmission of infection, and
feelings of alienation subsequent to clinic segregation (Griffiths, Armstrong, Carzino, & Robinson, 2004).

**Medical Treatment Adherence and Social Support**

Adherence to both IC guidelines, discussed above, and standard medical regimens are critical to the effective management of CF. Individuals with CF adhere to their medical treatment by following medical treatment regimens prescribed by their doctors. CF is among the most complex, time-consuming chronic conditions to manage, requiring substantial daily effort that takes between 2 to 4 hours per day (i.e., airway clearance, nebulized medications, oral medications) to complete (Modi & Quittner, 2006). Proper disease management also requires dietary changes to increase caloric intake to 110-200% of the recommended daily allowance (Stallings, Stark, Robinson, Feranchak, & Quinton, 2008). In addition to the daily treatment regimen, patients attend quarterly clinic visits. CF is also marked by frequent pulmonary infections which require intravenous (IV) antibiotic treatment and extended hospital stays (Quittner, Barker, Marcil, & Grimley, 2009). Specifically in children with CF, adherence to overall medical treatment regimen is about 50%, which is consistent with overall adherence rates in other chronic illness populations (Modi et al., 2006, Rapoff, 2009, Sawicki, Heller, Demars, & Robinson, 2015). The consequences of nonadherence are significant for these youth, given there is also a marked decrease in lung function, increase in hospitalizations, and increased morbidity (Quittner et al., 2009). Given the striking nature of this finding, it is essential to better understand factors that may promote or enhance treatment adherence. One factor deserving attention is social support, which has some empirical support as a factor promoting treatment adherence (Burroughs, Harris, Pontious, & Santiago, 1997; Ellis et al., 2007; Lewin et al., 2005). This makes logical sense, as assistance and support from peers and family can promote patient
adherence by encouraging optimism and self-esteem, buffering the stresses of being ill, reducing patient depression, and giving practical assistance (Gallant, 2003).

**Social Support: Various Components and Measurement**

There has been relatively little agreement among authors as to the precise theoretical and operational definition of the concept of social support (Hupcey, 1998). However, the most widely accepted definition, and the definition that will be adopted in this paper is described by Hupcey (1998) as: “A type of positive interaction or helpful behavior provided to a person in need of help or support.” Two important components of social support have been distinguished in the literature: (1) structural social support, and (2) functional social support (Cohen, 1988).

Structural social support includes both the sources of support (e.g., family, friends, teachers), and the density of the available social network (e.g., how well social members know each other; Cohen, 1988). In contrast, functional social support involves the qualitative characteristics of relationships (e.g., type of support provided and perceived helpfulness; Cohen, 1988), and is broken down into three main types of functional social support: instrumental support, emotional support, and informational support (Schaefer, Coyne, & Lazarus, 1981). Instrumental support can involve the provision of material aid (e.g., transportation, money, labor, and other tangible supports), or physical assistance with adherence related behaviors. Emotional support involves the verbal and nonverbal communication of caring and concern, such as “being there,” listening, showing concern, and empathizing. Lastly, informational support involves the provision of information used to guide or advice, such as providing patients with ways of managing their illness and coping with symptoms (Schaefer et al., 1981). Structural support has been identified as one component of social support; however research has primarily focused on the relation of functional social support and adherence which will be the focus of this study.
As noted previously, the superordinate construct of social support is composed of a variety of support domains and behaviors. Thus, specifying the type of social support is crucial for maintaining clarity in this body of literature. For instance, a study that examines only general (i.e., nonregimen-specific) social support may obtain a very different picture than one that assesses regimen-specific support behaviors (Burroughs et al., 1997). Regimen-specific support refers to support that specifically focuses on helping a child or adolescent manage a medical treatment, a treatment regimen, or the stresses associated with having a medical condition (La Greca, Bearman, & Moore, 2002). Instruments targeting social support typically assess overall supportive behaviors from friends, family, and health care providers. These instruments do not specifically index any regimen-specific support behaviors from friends, family, and health care providers and are limited in their ability to accurately assess the relation between social support and adherence. Although assessing overall levels of support is important, research utilizing measures of regimen-specific support behaviors are needed to more precisely assess the relation between social support and adherence (Bearman & La Greca, 2002; La Greca et al., 1995).

In addition to using non-standardized instruments, other studies relied on measures of only one domain of functional social support (e.g., emotional support) or combine domains of functional social support. Although it is important to consider the various domains of functional social support individually (i.e., instrumental, emotional, and informational social support), it is important for researchers to note the complexity of social support and the interconnectedness of each of the domains of functional social support (Burroughs et al., 1997). Therefore, it is important for studies to examine all of the functional social support domains together to understand how social support impacts adherence behaviors broadly.
Although most research on the relation between functional social support and patient adherence focuses on adults with a chronic illness, there is a relatively scant body of literature that examines this relationship in adolescents and young adults suffering from a chronic illness. In order to better understand how social support relates to adherence for adolescents and young adults with a chronic illness, a review of the research findings regarding the different types of functional support and the relation to medical adherence in children and adults is crucial. Also, the research to date on functional social support and adherence largely relied on children/adults with one type of chronic illness (i.e., diabetes, or asthma). One CF specific study examined the relationship between disease-specific social support and specific CF related adherence behaviors (Barker, 2010). Findings from this study suggest overall supportiveness (as measured by a composite score) from family and friends was related to measures of treatment adherence (Barker, 2010). Study findings suggest that perceiving support from family is related to better enzyme adherence and more time spent exercising, while perceiving support from friends is related to better adherence to enzymes, airway clearance, and aerosol medications. In order to better understand the potential unique contribution of different types of social support to medical treatment adherence within a population of individuals with cystic fibrosis, it is important to review the types of social support previously shown to relate to medical treatment adherence.

**Instrumental Support and Medical Adherence**

Numerous studies found a relationship between instrumental support and patient medical adherence, such that patients who report receiving more instrumental support are more likely to adhere to their medical regimen (Anderson, Auslande, Jung, Miller, & Santiago, 1990; Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Ellis et al., 2007; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Wiebe et al., 2005). Anderson and colleagues (1997)
interviewed 89 young adolescents with insulin-dependent diabetes mellitus (IDDM) and their families to assess the division of responsibility within families during a typical day for two tasks: insulin injections and blood glucose monitoring. The researchers found that parents who were more involved in IDDM management tasks (e.g., selecting dose and drawing up insulin, injecting insulin, and blood glucose monitoring) had children who more frequently adhered to their medical treatment regimen. La Greca et al. (1995) utilized the Diabetes Social Support Interview (DSSI) to assess adolescents’ reports of support received from family members and friends. Study findings suggest instrumental support of diabetes care (i.e., assistance with glucose testing/insulin shots, and meal plan/diet) among family members was a significant predictor of treatment adherence in this chronically ill sample of adolescents (La Greca et al., 1995). Also, several recent studies (Ellis et al., 2007; Helgeson et al., 2008; Wiebe et al., 2005) have further confirmed the relation between parental instrumental support for diabetes care and favorable treatment adherence outcomes. Considering these studies collectively, treatment management may be challenging for adolescents, and having the instrumental support of parents/family appears crucial.

**Emotional Support and Medical Adherence**

Few studies have evaluated the relationship between emotional social support and adherence in children and/or adults with a chronic illness. A review of this literature has yielded mixed results, where emotional social support and adherence behaviors are positively related (Lewin et al., 2005), or not related at all (Catz, Heckman, Kochman, & DiMarco, 2001; La Greca et al., 1995; Woller, Kruse, Winter, Mans, & Alberti, 1993). In a sample of 122 children with type 1 diabetes and their families, Lewin and colleagues (2005) investigated children’s perception of family emotional support (e.g., “my parent understands how I feel about having
diabetes”) and adherence to a diabetes management regimen (i.e., insulin administration/dose adjustment, blood-glucose monitoring, exercise, diet, and management of hypoglycemia) using the Diabetes Family Behavior Scale (DFBS; Waller et al., 1986). Results revealed a positive correlation between family emotional support and adherence, suggesting greater emotional support is associated with greater adherence to a variety of diabetes related recommendations (Lewin et al., 2005). Utilizing the previously discussed DSSI, La Greca and colleagues (1995) assessed adolescents’ reports of received emotional support from family members and friends. Surprisingly, the researchers found perceived emotional support, praise, and encouragement from peers was not related to adherence to diet recommendations, glucose testing, or hypoglycemia prevention in a sample of adolescents with IDDM. Also, similar findings have been displayed in the adult literature (Boyer, Friend, Chlouverakis, & Kaloyanides, 1990; Catz et al., 2001; Taal, Rasker, Seydel, & Wiegman, 1993), suggesting no relation between emotional social support and treatment adherence for adults suffering from a variety of chronic illnesses (i.e., human immunodeficiency virus (HIV), end stage renal disease, and rheumatoid arthritis). Overall, the majority of data suggests no relation exists between emotional support and adherence, and only one study suggests a significant relation exists.

**Informational Support and Medical Adherence**

Patients can obtain informational support (i.e., provision of information used to guide or advice) from family members, friends, physicians, and educational resources. With regard to family members and friends, limited research has attempted to evaluate the relationship between informational social support provided by a family member/friends and adherence in children and/or adults with a chronic illness. One study attempting to assess informational support in a sample of children with a chronic illness was conducted by La Greca and colleagues (1995).
These authors used the DSSI to assess adolescents’ reported support received from family members and friends for their diabetes care. Of the 17 categories on the DSSI, only one category was representative of informational support and asked the question, “do friends/family members provide disease specific information (e.g., gives me things to read, suggests ways to exercise).” Only two percent of adolescents report receiving informational support for each of the adherence tasks (i.e., insulin administration, blood glucose testing, following a meal plan, and exercising regularly). The authors believed this finding was not accurate and subject to reporting error or bias, therefore the informational support category was deemed unrepresentative of the population being studied and was not included in data analyses (La Greca, 1995). It is possible this figure is a true reflection of children in this study receiving limited informational support; however this interpretation should be considered cautiously. These findings suggest that children with a chronic illness may not be receiving informational support from friends or family regarding specific adherence related behaviors.

Although evidence suggests that children with a chronic illness are not receiving informational support that leads to improved adherence, a study conducted with adults suffering from a chronic illness found a relationship between family/friend informational support and adherence to a medical regimen. In a sample of adults with HIV, Singh and colleagues (1999) investigated the relation of patients’ perception of informational support from friends and family and adherence to antiretroviral medication prescriptions. The researchers found that adults who perceived receiving more informational support from friends and family had greater levels of antiretroviral medication adherence (Singh et al., 1999). Taken together, there is a dearth of studies suggesting a relation between family/friends instrumental social support and reported adherence outcomes for children with a chronic illness. In the adult literature preliminary
evidence suggests a relation between family/friend instrumental support and adherence does exist, although this initial research requires further empirical support.

Researchers have also assessed the relationship between informational support and treatment adherence by providing children with educational videotapes, picture books, and interactive computer-based programs designed to teach children how to manage a chronic illness (Guendelman, Meade, Benson, Chen, & Samuels, 2002; Holzheimer, Mohay, & Masters, 1998). Children with asthma who received informational support via educational video tapes, picture books, and interactive computer-based programs had better asthma related adherence than children in control groups who did not receive informational support (Guendelman et al., 2002; Holzheimer et al., 1998). These study findings suggest informational support received from educational videotapes, picture books, and computer-based programs are positively related to adherence in children with a chronic illness. These materials are specially designed to deliver information to children in an understandable and dynamic format. Thus, materials designed to clearly explain important factors to children with a chronic illness are useful tools in providing informational support.

**Knowledge Regarding Treatment**

Taken together, there are discrepancies in the literature relating various domains of social support and adherence. Some possible explanations for varying results found in studies include: conceptualization and measurement of the construct of social support, the measurement of adherence, small sample sizes, individual patient factors, and lack of theoretical framework. As suggested by Wallander (1992) pediatric psychology research has tended to neglect theory. However, researchers recommend that theoretical models be utilized in adherence research to integrate previously examined variables and strengthen research methodology (Finfgeld,
Wongvatanyu, Conn, Grando, & Russel, 2003). Several models have been offered for conceptualizing and understanding adherence behaviors (Weinstein, 1993), with the Health Belief Model (HBM) being one of the most widely-used models identified to explain and predict health related behaviors (Janz & Becker, 1984; Strecher & Rosenstock, 1997). The HBM is a value-expectancy theory suggesting that individuals who desire to avoid illness/get well (value), and have a belief that a specific health action would prevent/improve illness (expectation), will be more likely to adhere to their medical regimen (Becker & Janz, 1985; Rosenstock, 1990; Strecher & Rosenstock, 1997). The HBM includes several modifying individual patient factors: age, ethnicity, gender, socioeconomic status, and disease knowledge.

Of particular interest in the current study is the modifying individual patient factor of disease knowledge. Disease knowledge includes an accurate understanding of the treatment regimen tasks that comprise successful treatment adherence and the ability to perform adherence behaviors accurately (La Greca & Bearman, 2003). When adolescents are responsible for carrying out adherence behaviors on their own, knowledge about their disease may be a relevant variable to consider. Researchers have identified gaps in knowledge of disease management as one barrier to treatment adherence (Modi & Quittner, 2006). In two large, multicenter studies, adolescents with CF scored 55–60% on a knowledge measure of CF care management (Modi & Quittner, 2006; Quittner, Drotar, & Ieverson-Landis, 2004). Thus, a significant gap in knowledge exists. The positive association between knowledge of prescribed treatments and treatment-related behaviors has been described in health populations. Lorenz, Christensen, and Pichert (1985) found that diet-related knowledge predicted dietary adherence among children with diabetes. Similarly, La Greca and colleagues (1990) found that adolescents’ disease knowledge significantly predicted their own level of adherence with diabetes care. Moreover, Ieverson and
colleagues (1999) found a relationship between an accurate understanding of the treatment regimen and rates of adherence in a sample of patients with CF. Thus, patients with CF may need specific and accurate information about their disease in order to manage it on a daily basis. Taken together, disease knowledge appears to be an important modifying variable to consider when discussing adherence behaviors for adolescents and young adults with a chronic illness. There is a dearth of research examining disease knowledge in the context of social support and adherence in a CF population. Utilizing the Health Belief Model theory as a guide, the addition of CF disease knowledge as a potential modifying variable serves as a starting point to determine the relevance of CF disease knowledge in the context of social support and adherence behaviors. As increased disease knowledge appears to contribute to increased adherence behaviors, we will attempt to elucidate the relationship between social support and adherence by examining disease knowledge as a potential variable that may modify this relationship.

**Social Support and Implications of IC Guidelines**

Peer relations and close friendships play extremely important roles in adolescents’ emotional development (La Greca et al., 2002). Children and adolescents spend most of their daytime hours engaged in academic and leisure activities with peers and close friends (Berndt, 1982; Hartup, 1996), and these relationships represent a significant source of support for children and adolescents (La Greca et al., 2002). However, children and adolescents with chronic medical treatments often express concerns about the social impact of their condition and the possible interference of treatment adherence on their friendships (La Greca et al., 2002). Children and adolescents may even abstain from adherence related behaviors to blend in with healthy peers (La Greca et al., 2002). Barker and colleagues (2012) found peer support may not be available or accessed by all adolescents with CF. Study findings showed the majority (58%)
of adolescents with CF informed their entire friend network, however 25% told only a few select friends, and 17% had not voluntarily shared their diagnosis with their friends (Barker, Driscoll, Modi, Light, & Quittner, 2012). It is possible that the one in six adolescents who did not voluntarily disclose their diagnosis had limited access to treatment-related support from friends. Taken together, studies suggest children and adolescents, who are reluctant to discuss their chronic illness with friends, may be limiting their opportunities for obtaining important types of peer support.

Support from peers and close friendships has received little attention in the literature to date (Barker, Driscoll, Modi, Light, & Quittner, 2012; La Greca et al., 1995; La Greca et al., 2002). Adolescents with CF report more companionship support (e.g. acceptance, encouragement) from peers (Barker et al., 2012; Graetz et al., 2000). However, little is known about the roles peers play as facilitators to treatment adherence. Accordingly, it is vital for health care providers to be aware of the ways peer relations and close friendships affect children’s adherence to medical regimens (La Greca et al., 2002). Facilitating increased social support holds the promise of improving adherence, but more work is needed to understand which aspects of support are related to adherence outcomes.

Because individuals with a chronic illness can feel different from others (Massie, 1985), therapy groups are an effective way to provide individuals with opportunities for modeling, helping others, and relating to peers who share similar circumstances (Schaefer, 1999). Social support group attendance has been linked to improved survival rates and quality of life in chronic illness populations (Fawzy et al., 1993). Also, research suggests support from same-illness peers is beneficial and is associated with positive health outcomes (Clark et al., 1992). Anderson and colleagues assessed the effects of a same illness peer-group intervention on adherence in
adolescents with IDDM. Study findings suggest that participating in an intervention specifically with peers with the same medical condition can improve children’s health behaviors (Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989). Thus, it may be more beneficial to provide interventions for children with a chronic illness and same-illness peers to improve adherence to medical treatment regimens. However, in the case of Infection Control, social contact between CF patients is discouraged. Consequently, programs including interactive group sessions are no longer considered safe for children with CF because of the potential for patient-to-patient transmission of respiratory tract pathogens (Saiman et al., 2014). Thus, elimination of group-based activities and minimizing contact between patients has led to a loss of peer support. Acknowledging the potential psychosocial and medical impact of IC recommendations for people with CF and their families is critical. Although few studies have evaluated the impact of the current infection control guidelines on patients’ social and emotional functioning, social support has been shown to play a major role in facilitating adaptation to chronic diseases, including CF, and adherence to daily medical regimens (DiMatteo, 2004; Modi, Marcil, Slater, Drotar, & Quittner, 2008; Rosland, Kieffer, Israel, Cofield, Palmisano, Sinco, et al., 2008).

Although person-to-person contact between CF patients is discouraged, the World Wide Web represents a relatively new source of health information and support available online. Isolation of CF patients from each other has led Internet-savvy individuals to use new media as social forums to create social networks while avoiding the risk of person-to-person transmission. Online social networking can provide an opportunity for adults and children with CF to communicate with each other about personal issues and to give and receive valuable peer support outside the healthcare setting (Ferrin, Robinson, Hadjiliadis, Holsclaw, 2010; Saiman et al., 2014). The Pew Research Center (2013) found that 16% of internet users have gone online to
find individuals with similar health concerns. Young people are using new technologies at ever-increasing rates. According to a 2015 survey, 92 percent of young people use the internet daily, with 90 percent on social networking sites (Pew Internet American Life Project, 2015). With this increased access to social networking sites, it is possible for children with CF to seek out social support online as person to-person contact is discouraged. Absences from school, being teased, keeping their illness secret, and lack of access to peers with CF due to risk of infection can leave many adolescents with CF feeling isolated and alone. The enormous impact the diagnosis has on individuals with CF has prompted the development of several CF specific groups where patients/families can communicate online. Several CF social networking groups have been developed, however there has been no published evaluation of the types of social support perceived/received on these sites.

Much of the empirical attention regarding Internet use and chronic illness focuses on a variety of chronic illnesses (e.g., HIV/AIDS, arthritis, diabetes, irritable bowel syndrome, and cancer) within adult populations (Davison, James & Dickerson, 2000; Macias, Lewis, & Smith, 2005). These studies have been consistent in demonstrating that sharing information and emotional support are common functions of these virtual communities. One study examined instances where individuals (including children) with CF disclosed their illness anywhere on the Internet (Ravert & Crowell, 2008). These researchers found that adolescents (13–18 years) most frequently expressed psychosocial concerns and enlisted social support after disclosing that they have CF. However, more research is needed to examine the social network use of adolescents and young adults with CF regarding social support and to explore how social network experiences/exposure affects health related behaviors.
Present Study

Based on the foregoing review of literature on social support, adherence, and disease knowledge, the present study aimed to test a number of hypotheses. First, the study aimed to examine the type/amount of social support young people with CF seek out and receive while utilizing a social networking website. Second, the study aimed to examine the relationships among types of perceived social support, source of perceived social support, amount of perceived social support, level of both medical and IC adherence, and disease knowledge. No studies have examined how young people with CF make use of the social networking sites/groups and how they incorporate information from these sites into their lives. Therefore, this study aimed to clarify the nature of these relationships by considering how perceived social support is related to adolescents and young adult’s medical treatment adherence, IC adherence, and disease knowledge.

Hypotheses

**Hypothesis 1.** With the implementation of IC recommendations, which discourage patients from person-to-person contact, it is crucial to identify and provide supportive resources and interventions appropriate to meet the social needs of individuals with CF. Examination of social support in the types of communication taking place in the context of CF specific social networking groups has not yet been explored as a window into the needs and issues facing individuals living with CF. The present study seeks to investigate the content of CF specific social networking groups, specifically as it relates to social support. It is hypothesized that the majority of questions posted on a social networking website specifically focused on Cystic Fibrosis will be individuals seeking informational and emotional support. Also, it is hypothesized that the majority of responses posted on a CF specific social networking website
will be responding with informational and emotional support. This is hypothesized because previous research demonstrates that information and emotional support are common functions of virtual communities focused on adult populations (Davison, et al., 2000; Macias, et al., 2005).

**Hypothesis 2.** When examining overall perceived social support, it is hypothesized that overall perceived social support will be related to medical adherence, such that as overall social support increases, level of reported medical adherence will increase. This relationship is hypothesized because of previous research demonstrating that overall perceived social support has some empirical support as a factor promoting treatment adherence (Burroughs, Harris, Pontious, & Santiago, 1997; Ellis et al., 2007; Lewin et al., 2005).

**Hypothesis 3.** It is hypothesized that general CF knowledge will be related to medical adherence such that as overall general CF knowledge increases, level of reported medical adherence will increase. This relationship is hypothesized because previous research demonstrates a positive association between knowledge of prescribed treatments and treatment-related behaviors in various health populations (La Greca, Follansbee, & Skyler, 1990; Lorenz, Christensen, & Pichert, 1985).

**Hypothesis 4.** It is hypothesized that overall perceived emotional/informational support will be related to medical adherence, such that as overall perceived emotional/informational support increases, level of reported medical adherence will increase. This is hypothesized because previous research demonstrates a positive relationship between emotional and informational support and medical adherence (Guendelman et al., 2002; Lewin et al., 2005; Singh et al., 1999). Also, it is hypothesized that overall perceived instrumental support will be related to medical adherence, such that as overall perceived instrumental support increases, level of reported medical adherence will increase. This is hypothesized because previous research
demonstrates a positive relationship between instrumental support and patient medical adherence (Anderson, Auslande, Jung, Miller, & Santiago, 1990; Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Ellis et al., 2007; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Wiebe et al., 2005).

**Hypothesis 5.** It is hypothesized that overall perceived social support from family will be related to medical adherence, such that as overall perceived social support from family increases, level of reported medical adherence will increase. This is hypothesized because previous research demonstrates social support among family members is positively related to treatment adherence in chronically ill populations (Ellis et al., 2007; Helgeson et al., 2008; La Greca et al., 1995; Wiebe et al., 2005). Also, it is hypothesized that overall perceived social support from friends will be related to medical adherence, such that as overall perceived social support from friends’ increases, level of reported medical adherence will decrease. This is hypothesized because children and adolescents with chronic medical treatments often express concerns about the social impact of their condition and the possible interference of treatment adherence on their friendships (La Greca et al., 2002).

**Research Questions**

No studies have examined how young people with CF make use of social networking sites/groups and how they incorporate information from these sites into their lives. Due to the novelty of the current study, we ask several exploratory research questions to clarify the nature of study variables.

**Research Question 1a.** Do social network group members seek more informational support or emotional support from other group members when utilizing CF specific social networking groups?
**Research Question 1b.** Do social network group members provide more informational social support or emotional support to other group members utilizing CF specific social networking groups?

**Research Question 2a.** Is overall perceived social support related to IC adherence?

**Research Question 2b.** Is overall perceived social support related to disease knowledge?

**Research Question 3.** Is knowledge related to reported IC adherence?

**Research Question 4a.** Is overall perceived emotional/informational support related to IC adherence?

**Research Question 4b.** Is overall perceived instrumental support related to IC adherence?

**Research Question 5a.** Is overall perceived social support from online peers related to medical adherence?

**Research Question 5b.** Is overall perceived social support from family related to IC adherence?

**Research Question 5c.** Is overall perceived social support from friends related to IC adherence?

**Research Question 5d.** Is overall perceived social support from online peers related to IC adherence?

**Research Question 5e.** Is usage of CF specific social networking groups related to medical adherence?

**Research Question 5f.** Is usage of CF specific social networking groups related to IC adherence?

**Research Question 5g.** Is online peer support differentially related to medical adherence?
Research Question 5h. Is online peer support differentially related to IC adherence in comparison to friends and family social support?

Research Question 5i. Does disease knowledge moderate the relationship between social support and medical treatment adherence? Utilizing the Health Belief Model as a guide, we will attempt to elucidate the relationship between social support and adherence by examining disease knowledge as a potential modifying variable.

Research Question 5j. Does disease knowledge moderate the relationship between social support and IC adherence? Utilizing the Health Belief Model as a guide, we will attempt to elucidate the relationship between social support and adherence by examining disease knowledge as a potential modifying variable.
CHAPTER II

METHOD

Procedure

Regarding Hypothesis 1 and corresponding research questions, we developed a detailed code sheet (i.e., the Social Support Definition Sheet; See Appendix A) to capture instances of instrumental, emotional, and informational social support within message threads on CF specific social networking group websites. In selecting the CF specific social networking group websites, we compiled a list of CF specific social networking groups that provided message boards. Utilizing a social networking website (www.facebook.com), we identified eighteen different CF specific social networking groups with message boards. After a list of CF specific social networking groups with message boards were identified, threads (i.e., a series of messages/replies related in content that stem from an original post) from these boards were printed for coding. Message threads were coded anonymously (i.e., user names were not printed for coding). Threads were chosen based by identifying (i.e., copied and printed each thread beginning on the date of each search) up to three threads per message board per day from November 22, 2015 – March 1, 2016. The final sample consists of 1,662 individual messages from 400 message threads.

For the remaining study hypotheses and research questions, we recruited participants between the ages of 13-25 and parents (for those participants under the age of eighteen) from (1) the outpatient CF clinic at Akron Children’s Hospital, and (2) through an online website link that
was posted on CF specific social networking web pages. We chose this age range because nearly all children (97 percent) are online by the eighth grade (Jones & Fox, 2009). At the hospital, we approached parents (for those participants under the age of eighteen) and individuals over the age of eighteen at the CF Clinic during routine outpatient visits. The principle investigator consented participants after they checked in for their (or their child’s) appointment. We did not approach individuals in an acute medical crisis for participation at that time. We recruited participants on the internet by posting a website link on CF specific social networking pages which included consent forms for parent, children, and adults. We required participants with CF be under 25 years old. The survey was anonymous and no login name or password was required. Upon survey completion, we gave participants the option to give an email address to receive a ten dollar gift card. The procedures for collecting data were approved by the Institutional Review Boards of Kent State University and Akron Children’s Hospital.

We asked parents (with children under the age of eighteen) to complete a short demographic questionnaire to confirm they have a child age 13 to 18 years and to gain consent for the child to participate. We also asked parents to complete measures regarding their child’s internet usage, and treatment adherence. Upon completion of their portion of the survey, we asked parents to have their 13- to 18-year-old child with CF complete a longer series of questions designed to assess the child’s use of the internet, perceived social support, and treatment adherence. If there was more than one child with Cystic Fibrosis in a family, instructions asked that the child with a birthday closest to the current date finish the forms.

**Participants**

In this study, we recruited 60 individuals with CF between the ages of 13-25 and parents (for those children under the age of 18) for participation at Akron Children’s Hospital CF clinic
(30%) or through an online website link posted on CF specific social networking web pages (70%). Three participants did not complete all questionnaires and were subsequently removed from analyses. Therefore, we included 57 participants in study analyses (N = 18 participants from Akron Children’s Hospital CF clinic; N = 39 participants through an online website link). Descriptive information of all study variables can be found in Appendix N. We utilized independent sample t-tests and chi-square analyses to determine if there are significant differences between participants recruited online or in the CF clinic on demographic variables and adherence variables (i.e., medical adherence and IC adherence). All demographic and adherence variables are non-significant across groups.

Participants ranged in age from 13 to 25 years old, with a mean age of 18.55 years (standard deviation = 3.2); guardians (of participants under the age of 18) ranged in age from 30 to 61 years old, with a mean age of 45.4 years (standard deviation = 6.64). Further, the sample included 45% female participants and 55% male participants. The ethnic composition of the sample included: 85% Caucasian, 11.7% African American, 1.7% Latino/Hispanic, and 1.7% Asian/Pacific Islander. These ethnicity data are largely consistent with estimates of CF, which is a disease more predominant in Caucasians than members of ethnic minorities (Cystic Fibrosis Foundation, 2008). Of the guardians for those participants under the age of 18, the sample included: 68% biological mothers, 24% biological fathers, 4% step-parents, and 4% legal guardians. With respect to education level, 2.8% of the participants over the age of eighteen completed some high school, 8.3% completed high school/GED, 52.8% completed some college, 27.8% completed an associates/technical college degree, and 8.3% completed a graduate degree. Further, 45.9% of the participants over the age of eighteen reported living with their parents.
Measures

The Social Support Definition Sheet

We created the Social Support Definition Sheet (See Appendix A) specifically for the purpose of this study. Two coders utilized the Social Support Definition Sheet and corresponding definitions to code instances of informational support, emotional support, and instrumental support. We utilized the individual message posting as the unit of analysis. First, coders coded whether an individual message was either (1) social support being sought by an individual, or (2) social support being given by an individual. Next, coders coded whether the individual messages (either sought or received) were instances of informational support, instrumental support, or emotional support. In a pretest, the coders reviewed sets of printed sample conversation threads, with the two coders cross coding all threads of the pretest sample. In order to code, the researchers read each conversation thread, recorded relevant aspects (i.e., the three main types of social support) of each post or reply on the code sheet. Thirty percent of the threads were cross-coded for reliability. An interrater reliability analysis using the Kappa statistic was performed to determine consistency among raters (Kappa = .89 (p < .001), 95% CI (.75, .92). Kappa is above the minimal 80% agreement level (Riffe et al., 1998).

Demographic Questionnaire

We developed a demographic questionnaire (See Appendix B and C) specifically for the purpose of this study. Guardians or CF patients (over the age of eighteen) completed this form. We created two forms of the questionnaire: (1) parent version (Appendix B) and (2) patient version (Appendix C). Types of information the questionnaire assessed included: gender, age, ethnicity, marital status, education, level, occupation, insurance information, previous CF centers attended, dates of attendance, and IC procedures at the center(s).
The Knowledge of Disease Management-CF (KDM-CF)

The KDM-CF (Quittner et al., 2000; Appendix D) assessed adherence and disease management in CF. We utilized two versions of the KDM-CF in the current study: one for adolescents (ages 11-20), and one for parents of adolescents. These measures evaluated knowledge of disease management in 4 key areas: (1) General Health, (2) Lung Health, (3) Nutrition, (4) Treatments. This measure has strong internal consistency coefficients (DeLambo, Ievers-Landis, Drotar, & Quittner, 2004; Quittner et al., 2012). The internal consistency of the KDM-CF in the present sample is .84 as measured by Cronbach’s alpha.

Internet/Social Networking Usage Survey – Cystic Fibrosis

We created the Internet/Social Networking Usage Survey – Cystic Fibrosis (Appendix E and F) for the purpose of this study. We constructed both patient (Appendix E) and parent (Appendix F) versions of the questionnaire. The Internet/Social Networking Usage Survey assessed patients’ internet usage. Specifically, we assessed information regarding extent of internet, social networking website, and CF specific social networking group usage for each patient. Also, as usage of the internet can vary widely across different individuals; participants could respond “never” if they do not use the internet and “no” if they do not have an account on a social networking website. Responses were presented on a Likert scale with higher composite scores reflective of higher levels of internet/social networking use.

The Medical Outcomes Study (MOS) Modified Social Support Survey – Revised

We modified the MOS Social Support Survey - Revised (Shelbourne & Stewart, 1991; Appendix G, H, and I) from the MOS Modified Social Support Survey to adapt the questionnaire to a CF population. We developed a family (Appendix G), patient (Appendix H), and social network (Appendix I) version of the questionnaire for the purpose of this study.

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modeled the questionnaire primarily after the MOS Modified Social Support Survey created by Shelbourne and Stewart (1991); we added several questions because they enhanced the current measure by including constructs (i.e., adherence to a treatment regimen) not previously incorporated. Additional questions added to the measure were marked with an asterisk (*) in Appendices. The MOS Social Support Survey is a 19-item self-report measure used to assess social support along several dimensions: emotional support, tangible support, positive support, and affective support. This survey was developed to assess social support for patients with chronic conditions. Each of the four subscales are empirically reliable (all alphas >0.91), are relatively stable over time, and construct validity hypotheses were supported (Shelbourne & Stewart, 1991). The internal consistency of the MOS-Revised in the present sample is .97 for perceived family social support, .94 for perceived friend social support, and .93 for perceived social network social support as measured by Cronbach’s alpha. Additionally, we asked patients to rate how supportive they perceive each behavior to be after each item: not supportive, a little supportive, supportive, and very supportive. For the purpose of this study, we only utilized questions measuring perception of social support.

**The Infection Control Adherence Scale**

The Infection Control Adherence Scale (Masterson, 2007) assessed infection status/history and past/present physical contact with fellow CF patients. We utilized patient (Appendix J) and parent (Appendix K) questionnaires in the present study. For the purpose of this study, IC adherence is a categorical variable (i.e., “yes” IC adherence, or “no” IC nonadherent) which was calculated by examining the response to the question, “Do you have regular physical contact with another individual with CF (i.e., friend, sibling, or other relative?)” We altered the Infection Control Adherence Scale to include questions regarding current vs. past
contact with a friend, history of prior “camp” visits, and whether or not participant has a sibling diagnosed with CF. CF is a genetic disorder, and patient-to-patient transmission generally results from prolonged social contact, such as that between siblings or close friends (Speert et al., 2002). Therefore, we added the question regarding “sibling diagnosed with CF” because this variable may specifically affect several study variables including social support and IC adherence.

The Self Care Inventory – Cystic Fibrosis

We modified the Self Care Inventory – Cystic Fibrosis (CF-RAQ; Masterson, 2007) from the Self Care Inventory for Diabetes (DRAQ; LaGreca, Follansbee, & Skyler, 1990). We constructed parent (Appendix L), and patient (Appendix M) questionnaires. The CF-RAQ examined medical treatment adherence to various aspects of the CF medical treatment regimen including: airway clearance techniques, aerosol medications, inhalers, antibiotic aerosols, oral antibiotics, steroids, enzymes, nutritional supplements, and vitamins. Responses were presented on a Likert scale ranging from 1 (never do it as recommended) to 5 (always do it as recommended without fail), with higher composite scores reflective of higher levels of adherence to medical treatment. Composite scores are calculated by utilizing an average of participants responses, as participants could respond “not applicable” if a particular treatment was not part of their regimen. For the purpose of this study, medical treatment adherence is a continuous variable. Internal reliability of this measure was reported as .80 in a diabetes population; test-retest reliability was .77 over a two-week period (Davis et al, 2001). Validity data in a diabetes population demonstrated higher levels of self-care reportedly associated with better metabolic control (Davis et al, 2001). The internal consistency of the Self-Care Inventory-CF in the present sample was .91 as measured by Cronbach’s alpha.
Analysis Plan

In order to describe how informational and emotional support appeared in the context of individuals’ communications on social networking websites specifically focused on Cystic Fibrosis, we reported frequencies across coded social support variables. We described patterns and themes in individuals’ communications on CF specific social networking websites.

We conducted a robust number of data analyses, however this allowed us to be thorough in describing the data as many analyses were exploratory in nature. Pearson (for continuous outcome variables) and Spearman (for categorical outcome variable) correlation coefficients examined relationships between different variables in the analyses (see Appendix N) and tested for significant relationships between main study hypotheses and research question variables (overall perceived social support, general CF disease knowledge, emotional/informational social support, instrumental social support, overall perceived social support from family, friends, and online peers, usage of CF specific social networking groups, medical adherence, and IC adherence).

We investigated remaining study hypotheses and research questions using hierarchical linear and logistic regression (for categorical outcome variables). We chose hierarchical linear and logistic regression because it allowed for exploration of the impact of several predictor variables on a dependent variable, while controlling for impact of other variables (Tabachnick & Fidell, 2001). We entered predictor variables in progressive steps, and consulted the $R^2$ change statistic after each step. The $R^2$ change statistic yielded information on whether inclusion of these new predictor variables significantly improved the prediction of the outcome variable (Cohen & Cohen, 1975). A hierarchical linear regression examined whether the addition of perceived online peer social support explained additional variance in medical adherence after
controlling for friend social support and family social support. A hierarchical logistic regression examined whether the addition of perceived online peer social support explained additional variance in IC adherence after controlling for friend social support and family social support.

To examine whether CF specific disease knowledge moderated the relationship between overall perceived social support and relevant adherence variables (medical adherence and IC adherence) we conducted separate regressions for each type of adherence. We conducted a linear regression for the outcome variable of medical adherence. We entered the centered score of CF disease knowledge and overall social support in the first step, and the product of the CF disease knowledge and overall social support as the interaction term in the second step. We conducted a binary logistic regression for the outcome variable of IC adherence. We entered overall social support in the first step of the regression, CF disease knowledge in the second step, and IC adherence as the outcome variable. We are asking whether CF disease knowledge has a significant positive effect on predicting IC adherence above and beyond overall perceived social support.

A power analysis to determine required sample size in order to detect a medium effect size with an alpha of p = .05 and power = .80 with 3 predictor variables indicated a required sample of approximately 60 subjects.
CHAPTER III

RESULTS

Descriptive Data

With respect to medical adherence, 56% of the sample report adherence to their medical treatments “usually as recommended” or “always as recommended” based on information gathered via the Self-Care Inventory. Similarly, over half of the sample (53%) report IC adherence as measured by actively avoiding other CF patients. This is consistent with overall adherence rates in CF and other chronic illness populations (Modi et al., 2006, Rapoff, 2009, Sawicki, Heller, Demars, & Robinson, 2015). Descriptive statistics regarding participants self-report of relevant IC adherence variables gathered via the Infection Control Adherence Scale are displayed in Table 1.

Table 1

Descriptive Statistics for Participants Self-Report of Relevant IC Adherence Variables

<table>
<thead>
<tr>
<th>Variable (N = 57)</th>
<th>&quot;Yes&quot;</th>
<th>&quot;No&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a Multi-Drug Resistant Infection?</td>
<td>37 (65%)</td>
<td>20 (35%)</td>
</tr>
<tr>
<td>Do you have regular contact with CF patients?</td>
<td>20 (35%)</td>
<td>37 (65%)</td>
</tr>
<tr>
<td>Do you have a sibling diagnosed with CF?</td>
<td>22 (39%)</td>
<td>35 (61%)</td>
</tr>
<tr>
<td>Do you actively avoid CF patients?</td>
<td>38 (67%)</td>
<td>19 (33%)</td>
</tr>
</tbody>
</table>

We utilized chi-square analyses to determine if there are significant differences between participants who report IC adherence and those who do not report IC adherence on relevant IC
adherence variables (i.e., “Do you have a Multi-Drug Resistant Infection,” “Do you have regular contact with CF patients,” “Do you have a sibling diagnosed with CF,” “Do you actively avoid CF patients”; see Appendix N). Participants who report they do not adhere to IC guidelines are more likely to report they have a Multi-Drug Resistant Infection, $\chi^2 (1, N = 57) = 17.06, p<.001$. Participants who report they do not adhere to IC guidelines are more likely to report they have regular contact with CF patients, $\chi^2 (1, N = 57) = 17.50, p<.001$. Also, participants who report IC adherence are more likely to report they actively avoid CF patients, $\chi^2 (1, N = 57) = 25.65, p<.001$. Results of chi-square analyses revealed a trend between those participants who report IC adherence and those who do not report IC adherence on “Do you have a sibling with CF?” $\chi^2 (1, N = 57) = 3.80, p = .05$.

CF is a genetic disorder, and patient-to-patient transmission generally results from prolonged social contact such as that between siblings or close friends (Speert et al., 2002). In the present study, 39% of participants report having a sibling diagnosed with CF. As this represents a large portion of our data, we utilized independent sample t-tests and chi-square analyses to determine if there are significant differences between participants who report having a sibling diagnosed with CF and those who do not have a sibling diagnosed with CF on relevant study outcome variables (social networking usage, CF specific social networking usage, overall perceived social support, disease knowledge, medical adherence, relevant IC adherence variables, emotional/information social support, instrumental social support, friend social support, family social support, online peer social network support; see Appendix N). Regarding relevant IC adherence variables, participants who report they have a sibling diagnosed with CF are more likely to report they have a Multi-Drug Resistant Infection, $\chi^2 (1, N = 57) = 22.61, p<.001$, and have regular contact with another CF patient, $\chi^2 (1, N = 57) = 17.23, p<.001$. 
Participants with siblings ($M = 32.64$, $SD = 9.06$) report significantly lower CF disease knowledge scores than those without siblings ($M = 65.73$, $SD = 21.72$), ($t(35) = -6.44$, $p < .001$; $d = 1.99$). Also, participants with siblings ($M = 2.89$, $SD = .65$) report significantly less perceived family social support than those without siblings ($M = 3.65$, $SD = 1.01$), ($t(35) = -2.76$, $p < .05$; $d = .89$). However, all other variables are non-significant across groups.

Regarding internet use, 91.4% of study participants report using the internet more than once per week - every day. Regarding internet social network use, 91.4% of study participants report having at least one social networking account on the internet (63.5% of respondents have a social networking account for at least one year). Further, 54.4% of participants report being a member of a CF specific social networking group. Of those participants, 19.3% report using a CF specific social networking group every day, 24.6% report using a CF specific social networking group more than once per week, and 8.8% report using a CF specific social networking group once per week. Of the participants that report using a CF specific social networking group every day, 45.5% report spending 2-3 hours per day on the web page. We utilized independent sample t-tests and chi-square analyses to determine if there are significant differences between participants who report having a CF specific social networking account and those who do not on relevant study outcome variables (overall perceived social support, disease knowledge, medical adherence, relevant IC adherence variables, emotional/information social support, instrumental social support, friend social support, family social support, online peer social network support; See Appendix N). Regarding relevant IC adherence variables, participants who report they have a CF specific social networking account are more likely to report they have a Multi-Drug Resistant Infection, $\chi^2 (1, N = 57) = 3.99$, $p < .05$, and have regular contact with another CF patient, $\chi^2 (1, N = 57) = 15.12$, $p < .001$. Participants who report having
Hypotheses and Research Questions

Hypothesis 1

To test the hypothesis that instances of both informational and emotional support appear in the context of individuals’ communications on CF social networking websites, we calculated frequencies across coded variables. The final sample consists of 1,662 individual messages from 400 threads. As hypothesized, instances of informational support (57%) and emotional support (43%) appear in the context of individuals’ communications on CF social networking websites.

Research Questions 1a and 1b

In order to describe instances of the type of social support (i.e., informational, emotional) appearing in the context of individuals’ communications on CF social networking websites, we obtained frequencies across coded message threads. Overall, there are more instances of social network group members seeking informational support (60%) than emotional support (40%) when utilizing CF specific social networking groups. Similarly, there are more instances of social network group members providing more informational support (55%) than emotional support (45%) when utilizing CF specific social networking groups. We utilized chi-square tests to determine if there are significant differences between the types of social support individuals are seeking as well as providing (i.e., informational and emotional support). Individuals utilizing a CF specific social networking account are more likely to seek informational support versus emotional support, \( \chi^2 (1, N = 400) = 16.00, p<.001 \). Similarly, individuals utilizing a CF
specific social networking account are more likely to respond with informational support versus emotional support, $\chi^2 (1, N=945) = 8.76, p<.05$. 

**Hypothesis 2**

To test the hypothesis that overall perceived social support is related to self-reported medical adherence, we conducted a Bivariate Pearson correlation (see Table 2). Overall perceived social support is significantly related to self-reported medical adherence, such that as overall perceived social support increases, levels of reported medical adherence increase ($r = .417, p<.001$).

**Research Questions 2a and 2b**

We also explored the relationship between overall perceived social support and self-reported IC adherence (see Table 2) by utilizing a Spearman rank correlation. Overall perceived social support is significantly related to self-reported IC adherence ($r = .291, p<.05$). Also, we explored the relationship between overall perceived social support and reported general CF disease knowledge by utilizing a Bivariate Pearson correlation. We found a significant positive correlation between overall perceived social support and self-reported general CF disease knowledge ($r = .366, p<.01$).

**Table 2**

*Correlations of Overall Perceived Social Support, Adherence Variables, and General CF Knowledge (N = 57)*

<table>
<thead>
<tr>
<th>Overall Social Support</th>
<th>Medical Adherence</th>
<th>IC Adherence</th>
<th>General CF Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Social Support</td>
<td>1.00</td>
<td>0.417**</td>
<td>0.291*</td>
</tr>
</tbody>
</table>

*p<.05, **p<.01
Hypothesis 3

To test the hypothesis that self-reported general CF disease knowledge is related to self-reported medical adherence, we conducted a Bivariate Pearson correlation (see Table 3). General CF disease knowledge is significantly related to self-reported medical adherence, such that as general CF disease knowledge increases, levels of reported medical adherence increase \((r = .282, p<.05)\).

Research Question 3

We explored the relationship between general CF disease knowledge and self-reported IC adherence (see Table 3) by utilizing a Spearman rank correlation. General CF disease knowledge is significantly related to reported IC adherence \((r = .517, p<.001)\).

Table 3

*Correlations of General CF Knowledge and Adherence Variables (N = 57)*

<table>
<thead>
<tr>
<th></th>
<th>General CF Knowledge</th>
<th>Medical Adherence</th>
<th>IC Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>General CF Knowledge</td>
<td>1.00</td>
<td>0.282*</td>
<td>.517**</td>
</tr>
</tbody>
</table>

*p<.05, **p<.01

Hypothesis 4

To test the hypotheses that type of perceived social support is related to self-reported medical adherence, we conducted Bivariate Pearson correlations (see Table 4). Overall perceived emotional/informational social support is significantly related to self-reported medical adherence, such that as overall perceived emotional/informational social support increases, levels of reported medical adherence increase \((r = .562, p<.001)\). Overall perceived instrumental social support is significantly related to self-reported medical adherence, such that as overall perceived
instrumental social support increases, levels of reported medical adherence increase ($r = .327, p < .05$).

**Research Questions 4a and 4b**

We explored the relationship between type of perceived social support and self-reported IC adherence (see Table 4) by conducting a Spearman rank correlation. Overall perceived emotional/informational social support is significantly related to reported IC adherence ($r = .545, p = .001$). Also, we explored the relationship between overall instrumental social support and self-reported IC adherence by utilizing a Spearman rank correlation. Overall instrumental social support and reported IC adherence are not correlated.

**Table 4**

*Correlations of Types of Perceived Social Support and Adherence Variables (N = 57)*

<table>
<thead>
<tr>
<th></th>
<th>Medical Adherence</th>
<th>IC Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional/Information Support</td>
<td>.562**</td>
<td>.545**</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>.327*</td>
<td>.023</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01

**Hypothesis 5**

To test the hypotheses that source of perceived social support is related to self-reported medical adherence, we conducted Bivariate Pearson correlations (see Table 5). Overall perceived social support from family members is significantly related to self-reported medical adherence, such that as overall perceived social support from family members increases, levels of reported medical adherence increase ($r = .543, p < .001$). We found a significant positive correlation between perceived social support from friends and self-reported medical adherence,
such that as perceived social support from friends increases, levels of reported medical adherence increase ($r = .334, p<.05$).

**Research Question 5a**

We explored the relationship between perceived social support from online peers and self-reported medical adherence (see Table 5) by conducting a Bivariate Pearson correlation. We did not find a relationship between perceived social support from online peer and reported medical adherence.

**Research Questions 5b, 5c, and 5d**

We explored the relationship between source of perceived social support and self-reported IC adherence (see Table 5) by conducting a Spearman rank correlation. Overall perceived social support from family members was the only significant correlation with reported IC adherence ($r = .462, p<.001$).

**Table 5**

*Correlations of Source of Perceived Social Support and Adherence Variables*

<table>
<thead>
<tr>
<th>Source of Social Support</th>
<th>Medical Adherence</th>
<th>IC Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Social Support (N = 57)</td>
<td>.543**</td>
<td>.462**</td>
</tr>
<tr>
<td>Friend Social Support (N = 57)</td>
<td>.334*</td>
<td>-.004</td>
</tr>
<tr>
<td>Social Network Social Support (N = 42)</td>
<td>.157</td>
<td>.089</td>
</tr>
</tbody>
</table>

*p<.05, **p<.01

**Research Questions 5e and 5f**

We also explored the relationship between being a member of a CF specific social networking group and self-reported medical adherence and IC adherence by conducting a Bivariate Pearson correlation and a Spearman rank correlation respectively. Indicating
membership to a CF specific social networking group is not related to either self-reported medical or IC adherence.

**Research Questions 5g**

In order to explore whether perceived online peer social support is differentially related to self-reported medical adherence in comparison to perceived social support from friends and family, we conducted a hierarchical linear regression. Self-reported medical adherence was the outcome variable, perceived social support from family and perceived social support from friends were added as predictor variables in the first step of the regression, and perceived social support from online peers was added as a predictor variable in the second step. Perceived social support from family and friends significantly predicts medical adherence ($R^2 = .38, F(3, 38) = 11.72, p < .001$), and Table 6 contains the results of this regression. Higher perceived social support from family members is positively associated with self-reported medical adherence, ($\beta = .43, p < .05$). The addition of perceived social support from online peers did not significantly increase the variance explained in reported medical adherence. A final regression model predicts 38% of the variability in self-reported medical adherence.

**Table 6**

*Results of Hierarchical Linear Regression Predicting Medical Adherence (N = 57)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th>Model 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$B$</td>
<td>$SE\ B$</td>
</tr>
<tr>
<td>Family Social Support</td>
<td>.46</td>
<td>.16</td>
</tr>
<tr>
<td>Friend Social Support</td>
<td>.28</td>
<td>.21</td>
</tr>
<tr>
<td>Online Peer Social Support</td>
<td>-.11</td>
<td>.21</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.38***</td>
<td></td>
</tr>
<tr>
<td>$F$</td>
<td>11.71</td>
<td>.30</td>
</tr>
</tbody>
</table>

*$p < .05$, **$p < .01$, ***$p < .001$*
Research Question 5h

In order to explore whether perceived online peer social support is differentially related to self-reported IC adherence in comparison to perceived social support from friends and family, we conducted a hierarchical logistic regression. Self-reported IC adherence was the outcome variable, perceived social support from family and perceived social support from friends were added as predictor variables in the first step of the regression, and perceived social support from online peers was added as a predictor variable in the second step. The entry of perceived social support from friends and family members increases the variance accounted for in self-reported IC adherence, $\chi^2 (2) = 12.45, p < .05$, and results of this regression are displayed in Table 7. Using this model, there is a 78% accurate prediction rate of who would or would not adhere to their medical regimen. However, the entry of perceived social support from online peers did not significantly increase the variance accounted for in self-reported IC adherence, $\chi^2 (1) = .98, \text{n/s}$. Overall, the final model including perceived social support from online peers is significant, $\chi^2 (3) = 13.43, p < .05$. Using this model, there is a 76% accurate prediction rate of who does or does not adhere to their medical regimen. As an individual predictor, perceived social support from family members significantly predicts who would be adherent to their medical regimen, Wald Test (1) = 8.00, $p < .05$. For every one standard deviation unit increase in perceived family social support, the odds of adhering to the medical regimen increases by 6.4%.
Table 7

Results of Hierarchical Logistic Regression Predicting IC Adherence (N= 57)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th></th>
<th></th>
<th></th>
<th>Model 2</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β</td>
<td>Wald χ²</td>
<td>df</td>
<td>p</td>
<td>β</td>
<td>Wald χ²</td>
<td>df</td>
<td>p</td>
</tr>
<tr>
<td>Family Social Support</td>
<td>1.63</td>
<td>7.63</td>
<td>1</td>
<td>.01**</td>
<td>1.85</td>
<td>8.00</td>
<td>1</td>
<td>.01**</td>
</tr>
<tr>
<td>Friend Social Support</td>
<td>-.70</td>
<td>1.01</td>
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<td>.32</td>
<td>-.129</td>
<td>1.78</td>
<td>1</td>
<td>.18</td>
</tr>
<tr>
<td>Online Peer Social Support</td>
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<td></td>
<td></td>
<td>.65</td>
<td>4.30</td>
<td>1</td>
<td>.35</td>
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</tbody>
</table>

Test

<table>
<thead>
<tr>
<th></th>
<th>χ²</th>
<th>df</th>
<th>p</th>
<th></th>
<th>χ²</th>
<th>df</th>
<th>p</th>
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<td>Overall Model Evaluation</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likelihood Ratio Test</td>
<td>12.45</td>
<td>2</td>
<td>.00**</td>
<td></td>
<td>13.43</td>
<td>3</td>
<td>.00**</td>
</tr>
</tbody>
</table>

*p<.05, **p<.01

Research Question 5i

We conducted a regression to investigate whether general CF disease knowledge
moderates the association between overall perceived social support and self-reported medical
adherence. The final regression model predicts 25% of the variability in reported
medical adherence. There is a statistical trend when the interaction term of general CF disease
knowledge and overall perceived social support are added to the model, F (1,53)= 3.76, p= .058,
and Table 8 contains the results for this regression (See Appendix N for interaction figure).
Table 8

Summary of Regression Analysis Predicting Medical Adherence from interaction between Overall Perceived Social Support and General CF Disease Knowledge (N= 57)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th></th>
<th></th>
<th>Model 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
<td>β</td>
<td>B</td>
<td>SE B</td>
<td>β</td>
</tr>
<tr>
<td>Overall Perceived Social Support</td>
<td>.32</td>
<td>.12</td>
<td>.36**</td>
<td>.34</td>
<td>.11</td>
<td>.40**</td>
</tr>
<tr>
<td>General CF Disease Knowledge</td>
<td>.13</td>
<td>.12</td>
<td>.15</td>
<td>.14</td>
<td>.11</td>
<td>.16</td>
</tr>
<tr>
<td>Social Support * Disease Knowledge</td>
<td></td>
<td></td>
<td>-.21</td>
<td>.12</td>
<td>-.23</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
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<td></td>
<td>6.48</td>
<td>3.76</td>
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</tr>
</tbody>
</table>

*p<.05, **p<.01

Research Question 5j

We conducted a logistic regression analysis to investigate whether reported CF disease knowledge, over and beyond reported overall perceived social support, predicted reported IC adherence. Results showed that the proposed model was significant, $\chi^2 (2) = 18.79$, $p< .01$, and results of this regression are displayed in Table 9. Reported overall perceived social support did not increase the odds of reporting IC adherence. However as an individual predictor, reported CF disease knowledge significantly predicts reported IC adherence, Wald Test (1) = 11.66, $p = .001$. For every 1 standard deviation increase in reported CF disease knowledge, the odds of reporting IC adherence were increased by 5.3%.
Table 9

Summary of Logistic Regression Analysis Predicting IC Adherence from CF Disease Knowledge, Above and Beyond Overall Perceived Social Support (N = 57)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>e^B (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Perceived Social Support</td>
<td>0.32</td>
<td>0.52</td>
<td>1.38 (.50-3.78)</td>
</tr>
<tr>
<td>General CF Disease Knowledge</td>
<td>0.05*</td>
<td>0.02</td>
<td>1.05 (1.02-1.08)</td>
</tr>
<tr>
<td>\chi^2</td>
<td>18.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>df</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05
CHAPTER IV

DISCUSSION

Overview

Person-to-person contact between CF patients is discouraged due to infection control guidelines, however the World Wide Web represents a relatively new source of online health information and social support. Isolated internet-savvy individuals with CF can use new media as social forums to create social networks while avoiding the risk of person-to-person transmission. Social networking can provide an opportunity for adults and children with CF to communicate with each other about personal issues and to give/receive valuable peer support outside the healthcare setting (Saiman et al., 2014). Several online CF social networking groups have been developed; however, there is a dearth of published evaluations examining social network usage on these sites. The present study is an early step in understanding the types of social support individuals with CF seek out and receive while using social networking sites, as well as how social network exposure affects health related behaviors. The present study demonstrated informational support is more sought after by individuals with CF than emotional support while communicating with online peers. As this is a largely exploratory study, the present study also helped clarify the nature of these online relationships by considering how perceived social support is related to self-reported medical treatment adherence, IC adherence, and disease knowledge. The present study demonstrated online social network support is not related to medical or IC adherence. Also, current study findings suggest the need for more research regarding disease knowledge in the context of medical and IC adherence and overall
perceived social support. Additionally, the present study demonstrated that family social support is an important factor contributing to increased self-reported medical adherence and IC adherence. These findings highlight the importance of providing interventions aimed at increasing family social support in order to improve adherence behaviors. Overall, this study is one of the first to investigate how individuals with CF make use of the social networking sites and how they incorporate information from these sites into their lives and complex medical and infection control adherence routines.

**Instances of Social Support Online**

In the current study, individuals with CF reported both seeking out and receiving informational and emotional social support online. This finding is consistent with previous studies that demonstrated sharing information and emotional support are common functions of virtual communities (Davison, et al., 2000; Macias, et al., 2005; Ravert & Crowell, 2008). A previous study found that individuals with CF most frequently expressed psychosocial concerns on the internet and enlisted social support after disclosing that they have CF (Ravert & Crowell, 2008). However, the present study found individuals with CF both seek out and receive significantly more informational social support than emotional social support online. For example, many online social support seekers asked for support regarding specific prescription medications and adherence behaviors (e.g., “What are some bad side effects of Orkambi?” “Is it safe to put a few drops of essential oils in my nebulizer?” “I’ve increased my vest treatments, how do I make them as productive as possible?” and “I need help gaining weight, give me some ideas.”).

Although the current study did not specifically ask participants why they utilize the internet to discuss their disease, there are several possible explanations to current study findings
that individuals with CF seek out more informational support online. Perhaps in the current study, individuals with CF wanted to talk to same-illness peers who have the possibility of having first-hand experience adhering to CF specific disease regimens (e.g., taking a new prescription medication, or utilizing a vest). Also, it may have been easier for participants in the current study to ask about more “concrete” informational support instead of asking online peers who they have never met in person for emotional support. Again, precise explanations as to why more participants in the current study sought out informational support online is beyond the scope of the study.

It is important to consider possibilities as to why current study findings suggest individuals with CF are seeking more informational support than emotional support online. Patient-physician communication may be one factor contributing to current study findings. Previous research demonstrates that a portion of medical patients leave their doctors’ offices not understanding what they have been told and what they are supposed to do (Johnson & Carlson, 2004). This is an unfortunate situation, as good communication is crucial for appropriate follow-through by patients (Buckham, 2002). There are many barriers to effective patient-provider communication (DiMatteo, 1997). Unfortunately, economic realities dictate medical visits be quite brief, allowing little time for discussion (Mechanic, McAlpine, & Rosenthal, 2001). Also, it is possible that participants in this study feel their doctor is rushed or pressed for time and patients may not want to inconvenience busy providers. Some providers may discourage patients’ information seeking, even unintentionally by not establishing an atmosphere that encourages patient questions by interrupting or redirecting the topic of conversation (Marvel, Epstein, Flowers, & Beckman, 1999). It is also possible that many providers may be using too much jargon and overestimate their patients’ understanding of technical terms. Doctors and
nurses believe their explanations are clear; however patient misunderstanding can be a common phenomenon, one posing particular problems for individuals whose instructions regarding diagnosis, treatment, and medication are complex (Parker, 2000), as with CF. It is possible that medical professional forget that what seems obvious and simple to them may be obscure and complicated to many of their patients, especially with a complicated disease regimen as with CF. Perhaps individuals in the current study utilized CF specific social networking websites to gain clarity regarding information medical providers previously discussed with them. Moreover, medical providers may believe that patient information handouts and medication labels are helpful tools for communicating important patient information. However, previous research has demonstrated that medication labels and patient handouts are written at an eight to tenth grade level, while the average American adult is at an eighth grade reading level (Arnold et al., 2001; Davis et al., 2006; Farrell, Deuster, Donovan, & Christopher, 2008; Lokker et al., 2008; Sanders, Thompson, & Wilkinson, 2007). Again, perhaps in the current study individuals with CF were going online seeking information about information medical providers already provided.

On the contrary, some medical providers may spark patients’ interest in the subject matter, subsequently increasing the amount of time patients spend online seeking information support. Also, patients receiving changes in disease regimen behaviors may precipitate seeking out more informational support online. These explanations are speculatory in nature as the current study did not evaluate why participants go online seeking social support. However, they provide some plausible alternative accounts for present study findings that individuals with CF are utilizing CF specific social support groups online and seeking more informational support.

In a short period of time, the Internet has become an indispensable vehicle for making acquaintances and developing relationships. In our study sample, 91.4% of individuals with CF
have a social networking account, and 54.4% are members of CF specific social networking sites. Research suggests virtual relationships can be just as intimate as face-to-face ones and are sometimes closer (Bargh, McKenna, & Fitzsimons, 2002). Asking online peers for informational social support may be beneficial for several reasons. First, individuals with CF can log into their online CF social networking account anytime (day or night) whenever they think of a question and receive an answer relatively quickly. Individuals with a chronic illness, like CF, can feel different from others; therefore, they may feel more comfortable asking same-illness peers for informational support online. Moreover, online peers may be providing informational support and answering questions about medication and their treatment regimen in a manner that is better understood by patients (i.e., using more basic language). While the current study is limited to the content of individual message postings on a CF specific social networking site, future studies focusing on the accuracy of informational social support provided to individuals online by social networking peers may be of great interest. While further studies are needed to better understand the factors that contribute to seeking online social support and the accuracy of information provided, our findings suggest that individuals with CF are seeking a great deal of specific medication and adherence informational support online.

**Social Support and Medical Adherence**

Consistent with study hypotheses, overall reports of perceived social support is related to medical adherence. This makes logical sense, as assistance and support from peers and family can promote patient adherence by encouraging optimism and self-esteem, buffering the stresses of being ill, reducing patient depression, and giving practical assistance (Gallant, 2003). Similarly, this study found both informational/emotional and instrumental social support are related to medical adherence. Regarding instrumental support, this finding is consistent with
previous studies that found a relationship between instrumental support and patient medical adherence, such that patients who reported receiving more instrumental support were more likely to adhere to their medical regimen (Anderson, et al., 1990; Anderson, et al., 1997; Ellis et al., 2007; Helgeson, et al., 2008; La Greca et al., 1995; Wiebe et al., 2005). Treatment management may be challenging, especially for adolescents and young people, and having instrumental support (e.g., help getting out of bed, help preparing meals, and help with treatment regimen) appears crucial. There is a dearth of studies that evaluated the relationship between emotional/informational social support and adherence in children and/or adults with a chronic illness. A review of this literature has yielded mixed results (Catz, Heckman, Kochman, & DiMarco, 2001; La Greca et al., 1995; Lewin et al., 2005; Woller et al., 1993). However, current study findings suggesting a positive relationship between emotional/informational support and medical adherence are encouraging and have several clinical implications. As discussed previously, noncompliance may occur because patients fail to understand instructions as given. Also, if a patient has a negative attitude toward a physician or medical provider, the probability of noncompliance will increase (Fuertes, et al., 2007). When a working alliance is formed between patients, their families, and medical providers, however, then adherence is more likely to occur (Fuertes, et al., 2007). Therefore, in order to increase individuals’ adherence to their medical treatment regimen, future interventions should include: simplifying instructions, providing more rationale for instructions, and helping patients with emotional distress that may undermine adherence by “being there,” listening, showing concern, and empathizing.

Regarding sources of social support, current study findings show social support from family members and friends is significantly related to self-reported medical adherence, such that as overall perceived social support from family members’ and friends increases, levels of elf-
reported medical adherence increase. This finding is consistent with a previous study suggesting overall supportiveness from family and friends is related to measures of treatment adherence (Barker, 2010). These findings highlight the importance of encouraging family members and friends to continually support individuals with CF by providing instrumental, emotional, and informational social support. While more research is needed to investigate the CF specific social support behaviors related to medical adherence, our findings suggest that friends and family members play an important role in providing social support which, in turn, contributes positively to medical adherence.

**Social Support and IC Adherence**

Transmission-based IC precautions are of particular interest in the current study due to implementation difficulties and potential negative social consequences associated with isolating CF patients from one another (Miroballi et al., 2012). While the medical basis for adherence to IC recommendations is clear, there has been limited research on the impact of IC recommendations (Saiman et al., 2014). The present study found a positive relationship between overall perceived social support and IC adherence. Previous research has demonstrated a high proportion (70%) of individuals with CF felt they would uniquely benefit from friendships with fellow CF patients (Masterson et al., 2008). These data suggest that, when given the opportunity, individuals with CF are at risk for initiating or maintaining contact with other CF patients. In a similar study, patients reported the reasons for their ambivalence or disapproval with IC guidelines included social and emotional concerns related to not socializing with other CF patients, and inconclusive evidence regarding person-to-person transmission of infection (Griffiths, et al., 2004). However, in the current study, a high percentage (67%) of patients report they actively avoid another patient with CF. The inconsistency with this study finding
regarding active avoidance of other CF patients with prior study findings may be due to passage of time. Perhaps CF patients have become more accepting of and aware of IC guidelines since they were first introduced to the CF community. While more research is needed to further understand the psychosocial impact of IC guidelines, current study findings suggest individuals with CF are attempting to follow IC guidelines by actively avoiding other individuals with CF.

Further, results of the current study found a positive relationship between overall perceived social support and IC adherence, such that as perceived social support increases, levels of IC adherence increase. Although individuals with CF may benefit from social support provided by another individual with CF, friends and family members may be able to provide an exceptional level of social support. Also, it is possible that individuals are receiving social support from same-illness peers without coming into direct contact with them via the internet as 54.4% of our study sample reports being a member of a CF specific social support group. Overall, study findings suggest the majority of individuals with CF are actively avoiding other CF patients (as per IC guidelines) while reporting high levels of social support. Though these analyses were exploratory, future research would benefit from additional assessment of specific sources of social support to understand impact on specific IC adherence behaviors.

Regarding type of social support, this study found emotional/informational support is related to IC adherence. One explanation for this finding is that having more information about the importance of adhering to IC guidelines and feeling like people truly understand/empathize with guidelines recommending avoidance of other CF patients promotes IC adherence. The current study did not find a relationship between instrumental support and IC adherence. This makes logical sense as someone physically helping you (e.g., helping you get out of bed, getting your medication for you, taking you to the doctor) does not appear to impact whether or not you
choose to avoid another individual with CF. Though these analyses were exploratory, future research would benefit from additional assessment of specific types of social support to understand the impact on IC adherence.

Regarding source of social support, the present study found family social support is the only source of support related to IC adherence. One explanation for this finding is perhaps the perception of high social support from family members decreases the need to seek out disease-specific support. Overall, this study’s finding highlights the importance of interventions aimed at increasing family social support in order to promote IC adherence. See below for further discussion of the importance of family social support and adherence behaviors.

**Social Networking Social Support**

Although person-to-person contact between CF patients is discouraged, the World Wide Web represents a relatively new source of health information and support available online. The enormous impact the diagnosis has on individuals with CF has prompted the development of several CF specific groups where patients/families can communicate online. Several CF social networking groups have been developed, however there has been no published evaluation of how social network experiences/exposure affects health related behaviors. Current study findings suggest no relationship between usage of CF specific social networking groups and IC or medical adherence. Perhaps the information obtained by individuals who utilize social networking groups does not impact adherence behaviors, although future studies would benefit from replicating these findings with a larger CF sample.

**A Special Case: Family Social Support**

The present study sought to examine the impact of source (i.e., family, friend, online peer) of social support on both IC and medical adherence. Several study hypotheses support the
notion that perceived social support from family members is significantly related to both self-reported IC and medical adherence. While previous research has demonstrated the importance of family social support in relation to medical adherence behaviors, there have been no studies examining impact of source of support on IC adherence. Current study findings suggest that a high level of perceived family social support is related to increased medical and IC adherence regardless of friend or online peer social support. The current study is limited in that we only evaluated overall family social support and did not assess specific family relationships (i.e., parent, grandparent, sibling). Future studies would benefit from assessing the precise nature of family relationship impact on adherence behaviors. However, the current study findings suggest the importance of interventions including families to promote both medical and IC adherence.

The current study found individuals who report having a sibling with CF also report lower levels of perceived family social support than individuals with CF who do not report having a sibling with CF. One possible explanation for this finding is that individuals with CF do not exist in isolation as they are an integral part of the family system. This explanation is consistent with family systems theory (Bronfenbrenner, 1979). A major tenet of systems theory (Bronfenbrenner, 1977) is the notion of reciprocity, both between individuals and their environment and between individuals within the system. Routine stresses encountered by parents caring for a child with a chronic illness have been described (Eiser, & Berrenburg, 1995). It would be reasonable to believe the stresses encountered by parents caring for more than one child with CF are even more significant, consequently limiting parents ability to provide similar levels of social support to each child diagnosed with CF at the same time. Perhaps parents of multiple children diagnosed with CF provide more attention and support for the child who is more symptomatic at the time, leaving the other sibling to feel less supported. This study finding
highlights the need to provide additional support to families that have more than one child diagnosed with CF as decreased family social support can impact medical and IC adherence behavior.

**Disease Knowledge**

Previous research suggests disease knowledge is an important factor to consider when discussing adherence behaviors for adolescents and young adults with a chronic illness. As increased disease knowledge appears to contribute to increased adherence behaviors, the current study attempted to elucidate the relationship between social support and adherence by examining disease knowledge as a variable that may moderate this relationship. Current study findings yielded a statistical trend when the interaction term of CF disease knowledge and overall perceived social support is added to the overall model predicting medical adherence. Due to the lack of previous research in this area of literature, the addition of CF disease knowledge as a potential moderator served as a starting point to determine the relevance of this variable in the context of social support and adherence in the CF population. Moderator variables are typically introduced when there is an unknown, weak, or inconsistent relation between a predictor and a criterion variable (e.g., a relation holds in one setting but not in another, or for one subpopulation but not for another; Fairchild & MacKinnon, 2009). It is possible that the moderate correlation between the variables of overall perceived social support and CF disease knowledge impacted the moderation analysis. CF disease knowledge is a significant individual predictor variable in both models predicting medical and IC adherence. The positive association between knowledge of prescribed treatments and treatment-related behaviors has been described in various health populations and current study findings replicate these findings (Lorenz, Christensen, & Pichert, 1985; LaGreca et al., 1995; Ivers et al., 1999). This finding has important clinical implications,
as disease education as well as encouraging individuals with CF to learn more about their disease may promote adherence. Study findings suggest that online social network support does not relate to adherence behaviors, highlighting the importance of family, friends, and medical providers in providing knowledge to CF patients and helping them understand their disease and medical/IC regimens.

**Limitations and Conclusions**

Some limitations of the present study should be considered. One limitation is the exclusive utilization of self-report questionnaires may not provide the most ideally objective measure of medical and IC adherence behaviors. Self-report measures are easy to complete, inexpensive, and can be used with multiple informants. However, self-report measures are also vulnerable to reporting biases (Rand, 2000). There is evidence that responding in a socially desirable manner (i.e., wanting to please the health care provider) influences reports of adherence, leading to overestimations of adherence (LaGreca & Schuman, 1995). In the current study, it is possible that responses made in a socially desirable manner were minimized as a graduate student, not physicians, approached the participants. Moreover, the data collected online may not have been subjected reporting bias as the principle investigator did not meet the participants and all data was collected anonymously. There are multiple methods to study adherence including more objective measures (e.g., diary data, electronic monitoring). However without a gold standard of adherence measurement, self-report measures remain the most widely used adherence measure (Rapoff, 2009). As discussed above, several methods of assessment have been used to measure adherence behaviors; however, each method has strengths and weaknesses. Therefore, it is recommended that, along with self-report measures, future studies
utilize multiple measures of adherence (e.g. self-report questionnaires, electronic monitoring, diary data, and pharmacy refill) as a criterion for validation.

Another limitation of the current study is the small sample size. Although the current study was limited in number of participants, the sample size is consistent with other research conducted using a population of patients with CF and other pediatric chronic illnesses. Also, due to the ethnically homogeneous sample utilized in the present study, the generalizability of the findings may be limited. The sample of participants in the current study was relatively consistent with the ethnic composition of CF patients in the population. In addition, the sample may have been biased because only patients who came to the CF clinic for a well visit were approached to participate, possibly eliminating participants who were experiencing more severe symptoms of CF. However, the present study did collect data anonymously from the Internet and online participants were not asked whether or not they were in acute medical care at the time they submitted their response, possibly correcting for any bias that may have occurred with participants in the clinic.

The present study replicates previous findings that overall social support, type of social support, source of social support, and disease knowledge are important factors relating to medical adherence. This study adds to the literature by demonstrating that increased social support, especially from family members, also contributes to IC adherence. These findings highlight the importance of providing interventions aimed at increasing family social support in order to improve not only medical adherence behaviors, but also IC adherence. The current study is limited in that we only evaluated overall family social support and did not assess specific family relationships (i.e., parent, grandparent, sibling). Future studies would benefit from assessing the precise nature of family relationship and adherence behaviors. The current study
found individuals who report having a sibling with CF also report lower levels of perceived family social support. The current study raises the possibility that families that have more than one child diagnosed with CF may need more support, as decreased family social support can impact medical and IC adherence behavior. Future studies would benefit from assessing the precise nature of the sibling relationship and its relationship with adherence and social support variables.

Overall, this study is one of the first to investigate how individuals with CF make use of the social networking sites and how they incorporate information from these sites into their lives and complex medical and infection control adherence routines. The present study demonstrated informational support is more sought after by individuals with CF than emotional support while communicating with online peers. While the current study is limited to the type of social support sought after/given in individual message postings on a CF specific social networking site, future studies focusing on the accuracy of informational social support provided to individuals online by social networking peers may be of great interest and have many clinical implications. While further studies are needed to better understand the factors that contribute to seeking online social support and the accuracy of information provided, our findings suggest that individuals with CF are seeking a primarily specific medication and adherence informational support online. This study finding has important clinical implications and suggests health care providers may want to continually inquire whether patients have questions, or comments about different portions of their medical regimen because these patients may be going online seeking/receiving information that may not be accurate. Overall, this study is one of the first to investigate how individuals with CF make use of the social networking sites and how they incorporate information from these sites into their lives and complex medical and infection control adherence routines. Future
research should be dedicated to better understanding social networking use of patients with a chronic illness and how social networking use impacts daily medical behaviors.
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APPENDIX A

SOCIAL SUPPORT CODE SHEET
APPENDIX A

Social Support Code Sheet

Emotional support involves the verbal and nonverbal communication of caring and concern, such as “being there,” listening, showing concern, and empathizing.

Informational support involves the provision of information used to guide or advice, such as providing patients with ways of managing their illness and coping with symptoms.

Instrumental support involves the provision of material aid (e.g., transportation, money, labor, and other tangible supports), or physical assistance with adherence related behaviors.
APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE – PATIENT VERSION
# APPENDIX B

## Demographic Questionnaire – Patient Version

1. **Your** date of birth ______/_______/ Month Year  
2. **Your** gender □ Male □ female

3. **Your** racial or ethnic background:  
   - □ African-American  
   - □ American Indian  
   - □ Asian/Pacific Islander  
   - □ Caucasian  
   - □ Latino/Hispanic  
   - □ South Asia/Asian Indian  
   - □ Other ____________

4. **Your** years of education:  
   - □ Middle School  
   - □ Some High School  
   - □ High School/GED  
   - □ Some College  
   - □ Associates degree/Technical School  
   - □ 4-year College Degree  
   - □ Post-College Degree  
   - □ Other ____________

5. Your type of medical insurance coverage:  
   - □ Medicaid  
   - □ Medicaid-HMO  
   - □ Private Insurance (through employer)  
   - □ Self-pay

6. Are **you** employed:  
   - □ Part Time (less than 35hr/wk)  
   - □ Full Time (35hr/wk or more)  
   - □ Not working outside of home

7. What is **your** occupation?  
   ____________________________

8. How did you hear about this study?  
   - □ Online  
   - □ While at my CF clinic

9. Have you changed CF centers in the past 5 years?  
   - □ Yes  
   - □ No

10. If yes, what were the Infection Control Procedures at the Center?  
    Check all the IC procedures that applied at your previous CF center:
    - □ Wearing surgical masks while at the clinic  
    - □ Discouraging social contact between individuals with CF  
    - □ Isolation of individuals with Burkholderia cepacia  
    - □ Emphasizing handwashing and equipment sanitation
11. With whom do you live?

- Spouse/Partner
- Parent(s)
- Friend(s)
- Dorm/College Roommate
- Live alone

12. Are you dependent on someone else for your support?

- Yes
- No

### IF YOU LIVE WITH YOUR PARTNER

**ANSWER THE QUESTIONS BELOW:**

13. What is your partner's years of education:

- Some High School
- High School/GED
- Some College
- Associates degree/Technical School
- 4-year College Degree
- Post-College Degree
- Other ____________

14. Is your spouse/partner employed:

- Part Time (less than 35hr/wk)
- Full Time (35hr/wk)
- Not working outside home

15. What is your spouse/partner's occupation?


### IF YOU LIVE WITH A PARENT(S) OR ARE SUPPORTED BY YOUR PARENTS

**ANSWER THESE QUESTIONS:**

13. What is the highest education level attained by either of your parents?

- Some High School
- High School/GED
- Some College
- Associates/technical Degree
- 4-year College Degree
- Post-College Degree
- Other ____________

14. Is one of your parents employed:

- Part Time (<35hr/wk)
- Full Time (35hr/wk)
- Not working

15. What is that parent’s occupation?


16. What is your total household income?

- Less than $10,000
- $10,000 to $19,999
- $20,000 to $29,999
- $30,000 to $39,999
- $40,000 to $49,999
- $50,000 to $59,999
- $60,000 to $69,999
- $70,000 to $79,999
- $80,000 to $89,999
- $90,000 to $99,999
- $100,000 to $149,999
- $150,000 or more
APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE – PARENT VERSION
APPENDIX C

Demographic Questionnaire – Parent Version

1. **Your** date of birth ______/_______/ Month Year

2. **Child’s** date of birth ______/_______/ Month Year

3. Relationship to child:
   - □ Biological Mother
   - □ Biological Father
   - □ Step-Mother
   - □ Step-Father
   - □ Guardian
   - □ Other ____________

4. **Child’s** gender □ Male □ female

5. **Your** racial or ethnic background:
   - □ African-American
   - □ American Indian
   - □ Asian/Pacific Islander
   - □ Caucasian
   - □ Latino/Hispanic
   - □ South Asia/Asian Indian
   - □ Other ____________

6. **Child’s** racial or ethnic background:
   - □ African-American
   - □ American Indian
   - □ Asian/Pacific Islander
   - □ Caucasian
   - □ Latino/Hispanic
   - □ South Asia/Asian Indian
   - □ Other ____________

7. **Your** years of education:
   - □ Some High School
   - □ High School/GED
   - □ Some College
   - □ Associates degree/Technical School
   - □ 4-year College Degree
   - □ Post-College Degree
   - □ Other ____________

8. **Child’s** grade in school____

9. Your type of medical insurance coverage:
   - □ Medicaid
   - □ Medicaid-HMO
   - □ Private Insurance (through employer)
   - □ Self-pay

10. Do you have a spouse/partner living in the home?
   - □ Yes
   - □ No
11. Are you employed:
   ☐ Part Time (less than 35hr/wk)
   ☐ Full Time (35hr/wk or more)
   ☐ Not working outside of home

12. Is your spouse/partner employed:
   ☐ Part Time (less than 35hr/wk)
   ☐ Full Time (35hr/wk or more)
   ☐ Not working outside of home

13. What is your occupation?

14. What is your spouse/partner's occupation?

15. Your partner’s years of education:
   ☐ Some High School
   ☐ High School/GED
   ☐ Some College
   ☐ Associates degree/Technical School
   ☐ 4-year College Degree
   ☐ Post-College Degree
   ☐ Other __________

16. Have you changed CF centers in the past 5 years?
   ☐ Yes
   ☐ No

17. If yes, what were the Infection Control Procedures at the Center?
   Check all the IC procedures that applied at your previous CF center:
   ☐ Wearing surgical masks while at the clinic
   ☐ Discouraging social contact between individuals with CF
   ☐ Isolation of individuals with Burkholderia cepacia
   ☐ Emphasizing handwashing and equipment sanitation
APPENDIX D

KNOWLEDGE OF DISEASE MANAGEMENT-CF (KDM-CF)
APPENDIX D

Knowledge of Disease Management-CF (KDM-CF)

For each question, please read all the answer choices carefully before choosing the one answer you think is best.

1) Pulmonary function tests (PFTs) are a fancy name for tests that:
a. Show how your adolescent’s lungs are working
b. Only need to be done once in a while
c. Depend on your adolescent’s effort in blowing
d. Answers a and c

2) Most of the food your adolescent eats is absorbed in the:
a. Stomach
b. Intestines
c. Liver

3) Undigested food will pass through your adolescent’s digestive system if he/she takes:
a. Too many enzymes
b. Too few enzymes
c. The right amount of enzymes
d. Enzymes just before he/she eats

4) Which of the following is a sign that your adolescent’s body is losing too much salt?
a. Weakness
b. Fever
c. Muscle cramps
d. Abdominal pain
e. Answers b and c
f. All of the above

5) People with CF should eat _______ snack(s) per day.
a. 1
b. 2
c. 3
d. More than 4

6) Airway clearance:
a. Keeps your adolescent’s body from producing mucus
b. Helps prevent lung infections
c. Should be done only when your adolescent is sick
d. Can be combined with any inhaled treatment
7) Inhaled antibiotics are generally most effective if done:
   a. Before airway clearance
   b. After airway clearance
   c. In the morning

8) Stomach cramps and gas can be signs of hunger and:
   a. Overeating
   b. A lack of vitamins
   c. Poorly digested fat
   d. Do not need treatment

9) When your adolescent exercises, he/she should:
   a. Eat more salt
   b. Pay attention to his/her breathing
   c. Sit down frequently and rest
   d. Drink more water
   e. Answers a and d

10) The CF bacteria in your adolescent’s lungs will always be killed with IV antibiotics.
    a. True
    b. False

11) If your adolescent coughs up a small amount of blood on a Friday night:
    a. Your adolescent should do his or her nebulized treatments and airway clearance
    b. Wait and see if it happens again
    c. You or your adolescent should contact the CF doctor on call
    d. You or your adolescent should call the CF clinic to make an appointment

12) Bronchodilators are used to:
    a. Open your adolescent’s airways
    b. Reduce mucus
    c. Prevent cough
    d. Clear up a stuffy nose

13) If your adolescent’s body is not digesting fat from the foods he/she eats, his/her stools may:
    a. Float
    b. Change color
    c. Sink
    d. Smell bad
    e. Not change
    f. Answers a, b, and d

14) For your adolescent to make the most out of his/her clinic visit, he/she should:
    a. Write down his/her questions before going to the clinic visit
    b. Ask the CF Team to write down changes in your adolescent’s treatment plan
    c. Keep a journal or write down changes in your adolescent’s health
    d. Ask questions if you don’t understand something
    e. Answers a and d
    f. All of the above
15) Which of the following prevents lung damage?
   a. Hypertonic saline
   b. Enzymes
   c. Airway clearance
   d. Exercise
   e. Eating more calories

16) How can your adolescent decrease the number of lung infections he/she gets?
   a. Staying away from people who are sick
   b. Trying to cough less
   c. Keeping up with his/her airway clearance
   d. Answers a and c
   e. All of the above

17) The CF Team is always talking about your adolescent’s BMI (body mass index) percentile, which:
   a. Should be the same as your adolescent’s age
   b. Comes from measuring your adolescent’s weight
   c. Should be at or above the 50th percentile for your adolescent’s age
   d. Should be between the 10th-25th percentile for your adolescent’s age
   e. Answers b and c

18) Stress, lots of homework, or problems with a friend can affect your adolescent’s:
   a. Eating
   b. Mood
   c. Health
   d. Answers b and c
   e. All of the above

19) Exercise can replace regular airway clearance.
   a. True
   b. False

20) Changes in your adolescent’s mucus, cough, or energy levels:
   a. Should be watched until the next clinic visit
   b. Can mean he/she is getting an infection
   c. Show that he/she needs to eat more

21) Foods that contain the most energy/calories are:
   a. Fats
   b. Carbohydrates
   c. Proteins

22) Inhaled medications like Pulmozyme® and hypertonic saline:
   a. Treat bacteria in the lungs
   b. Help remove mucus from the lungs
   c. Improve appetite
   d. Can replace airway clearance
23) Your adolescent’s CF Team will check his/her blood glucose:
   a. To see if he/she is eating enough
   b. Because people with CF have a higher chance of developing diabetes
   c. To see if your adolescent is doing his/her treatments
   d. To see if your adolescent needs more vitamins
   e. All of the above

24) Timing is everything; what is the right order to take the following treatments?
   a. Airway clearance, inhaled antibiotics, inhaled short-acting bronchodilators
   b. Inhaled short-acting bronchodilators, airway clearance, inhaled antibiotics
   c. Inhaled antibiotics, inhaled short-acting bronchodilators, airway clearance

25) When your adolescent might have a pulmonary exacerbation:
   a. Wait a week and see if he/she gets better
   b. Your adolescent should take extra vitamins
   c. You or your adolescent should call the CF Team when he/she develops a fever
   d. You or your adolescent should call the CF Team right away

26) Teens with CF should eat:
   a. Up to twice as much food as teens without CF
   b. The same amount of food as teens without CF
   c. More fat than teens without CF
   d. Less milk and cheese than teens without CF
   e. Answers a and c

27) When your adolescent feels stressed, it may help him/her to:
   a. Ignore it
   b. Act out (yelling, hitting)
   c. Do something fun
   d. Talk to someone
   e. Answers a and b
   f. Answers c and d

28) It is best for your adolescent to take enzymes:
   a. As soon as he/she remembers them
   b. At the beginning of a meal or snack
   c. During a meal or snack
   d. Soon after eating

29) With CF, coughing:
   a. Should be controlled with cough medicines
   b. Can make others sick
   c. Makes it harder for your adolescent to fight infections
   d. Helps your adolescent spit mucus out

30) One way to add calories to scrambled eggs is to:
   a. Mix them with 2% milk instead of whole milk
   b. Add grated cheese
   c. Add salt and pepper
   d. Add vegetables
31) It is important for your adolescent to be open and talkative with his/her CF Team because:
   a. Your adolescent knows the most about his/her body
   b. The team is nosy about your adolescent’s life
   c. The team needs to get information from your adolescent
   d. It helps the clinic visits go faster
   e. Answers a, c, and d
   f. All of the above

32) Enzymes should be kept in a cool, dark place.
   a. True
   b. False

33) To avoid getting new CF bacteria in his/her lungs, your adolescent should:
   a. Not hang out with others who have CF
   b. Cough into tissues and throw them away
   c. Stay home as much as possible
   d. Answers a and b
   e. All of the above

34) Teens with CF need to eat more because:
   a. Some energy is lost when food is not properly digested
   b. Their metabolism is faster
   c. They have to fight off infections
   d. Their appetites are naturally bigger
   e. Answers a, b, and c

35) People with CF take vitamins A, D, E, and K because these vitamins:
   a. Can be poorly absorbed from food
   b. Need extra water to be absorbed
   c. Are not found in foods people normally eat
   d. Answers a and b

Knowledge of Disease Management-CF Parent of Adolescent Version 3.0
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APPENDIX E

INTERNET/SOCIAL NETWORKING USAGE SURVEY – PATIENT VERSION
APPENDIX E

Internet/Social Networking Usage Survey – Patient Version

1. How often do you use the internet over the past month?

<table>
<thead>
<tr>
<th>Everyday</th>
<th>More than once a week</th>
<th>Once a week</th>
<th>Once a month</th>
<th>Less than once a month</th>
<th>Never</th>
</tr>
</thead>
</table>

2. Was your internet usage over the past month typical?

Yes

No

* If NO

Do you usually use the internet more or less than reported?

More

Less

3. If you use it everyday, how many hours do you use it for?

Less than one hour a day

1-2 hours per day

2-3 hours per day

3-4 hours per day

More than 4 hours a day

4. Do you have an account on a social networking website (e.g., Facebook or Myspace)?

Yes

No

*If you answered No, please skip to next questionnaire.

5. How long have you had your account on a social networking website (e.g., Facebook or Myspace)?

Less than 6 months

Between 6 months and 1 year

At least 1 year

6. How often do you use social networking websites (e.g., Facebook or Myspace)?

Everyday

More than once a week

Once a week

Once a month

Less than once a month

7. If you use it everyday, how many hours do you use it for?

Less than one hour a day

1-2 hours per day

2-3 hours per day

3-4 hours per day

More than 4 hours a day
8. Are you a member of any Cystic Fibrosis specific groups on a social networking website?
   Yes  No

9. When you are on a social networking website, how often do you look at Cystic Fibrosis specific group pages?

<table>
<thead>
<tr>
<th></th>
<th>Everyday</th>
<th>More than once a week</th>
<th>Once a week</th>
<th>Once a month</th>
<th>Less than once a month</th>
</tr>
</thead>
</table>

10. If you look at Cystic Fibrosis specific group pages everyday, how many hours do you look at them for?

<table>
<thead>
<tr>
<th>Less than one hour a day</th>
<th>1-2 hours per day</th>
<th>2-3 hours per day</th>
<th>3-4 hours per day</th>
<th>More than 4 hours a day</th>
</tr>
</thead>
</table>
APPENDIX F

INTERNET/SOCIAL NETWORKING USAGE SURVEY – PARENT VERSION
APPENDIX F

Internet/Social Networking Usage Survey – Parent Version

1. How often does your child use the internet over the past month?

<table>
<thead>
<tr>
<th>Everyday</th>
<th>More than once a week</th>
<th>Once a week</th>
<th>Once a month</th>
<th>Less than once a month</th>
<th>Never</th>
</tr>
</thead>
</table>

2. Was your child’s internet usage over the past month typical?

Yes  | No

* If NO

Do they usually use the internet more or less than reported?

More | Less

3. If your child uses the internet everyday, how many hours does your child use it for?

<table>
<thead>
<tr>
<th>Less than one hour a day</th>
<th>1-2 hours per day</th>
<th>2-3 hours per day</th>
<th>3-4 hours per day</th>
<th>More than 4 hours a day</th>
</tr>
</thead>
</table>

4. Do you child have a social networking account (e.g., Facebook or Myspace)?

Yes  | No

*If you answered No, please skip to next questionnaire.

5. How long has your child had a social networking account (e.g., Facebook or Myspace)?

<table>
<thead>
<tr>
<th>Less than 6 months</th>
<th>Between 6 months and 1 year</th>
<th>At least 1 year</th>
</tr>
</thead>
</table>

6. How often does your child use social networking websites (e.g., Facebook or Myspace)?

<table>
<thead>
<tr>
<th>Everyday</th>
<th>More than once a week</th>
<th>Once a week</th>
<th>Once a month</th>
<th>Less than once a month</th>
</tr>
</thead>
</table>

7. If your child uses social networking websites every day, how many hours does he/she use them for?

<table>
<thead>
<tr>
<th>Less than one hour a day</th>
<th>1-2 hours per day</th>
<th>2-3 hours per day</th>
<th>3-4 hours per day</th>
<th>More than 4 hours a day</th>
</tr>
</thead>
</table>
8. Is your child a member of any Cystic Fibrosis specific groups on social networking websites?
Yes  No

9. When your child is on social networking websites, how often does he/she look at Cystic Fibrosis specific group pages?

<table>
<thead>
<tr>
<th>Everyday</th>
<th>More than once a week</th>
<th>Once a week</th>
<th>Once a month</th>
<th>Less than once a month</th>
</tr>
</thead>
</table>

10. If your child looks at Cystic Fibrosis specific group pages every day, how many hours does he/she look at them for?

<table>
<thead>
<tr>
<th>Less than one hour a day</th>
<th>1-2 hours per day</th>
<th>2-3 hours per day</th>
<th>3-4 hours per day</th>
<th>More than 4 hours a day</th>
</tr>
</thead>
</table>
APPENDIX G

MOS SOCIAL SUPPORT SURVEY REVISED – FAMILY VERSION
APPENDIX G

MOS Social Support Survey Revised – Family Version

People sometimes look to their family for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you from your family if you need it within the past month? Circle the answer that best fits:

1. You can count on your family to listen to you when you need to talk about having CF.
   None of the time / A little of the time / Some of the time / Most of the time / All of the time
   How supportive is your family when you do talk to them about having CF?
   Not supportive / A little supportive / Supportive / Very supportive

2. Your family gives you information to help you understand your CF.
   None of the time / A little of the time / Some of the time / Most of the time / All of the time
   How supportive is your family when they give you information to help you understand your CF?
   Not supportive / A little supportive / Supportive / Very supportive

3. Your family gives you good advice about your CF.
   None of the time / A little of the time / Some of the time / Most of the time / All of the time
   How supportive is your family when they give you advice about your CF?
   Not supportive / A little supportive / Supportive / Very supportive

4. Your family encourages you to do a good job of taking care of your CF.*
   None of the time / A little of the time / Some of the time / Most of the time / All of the time
   How supportive is your family when they encourage you to do a good job taking care of your CF?
   Not supportive / A little supportive / Supportive / Very supportive
5. Your family is available to listen to concerns or worries about your CF care.*

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when listen to concerns or worries about your CF care?

Not supportive / A little supportive / Supportive / Very supportive

6. Your family understands when you sometimes make mistakes in taking care of your CF.*

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they understand you sometimes make mistakes in taking care of your CF?

Not supportive / A little supportive / Supportive / Very supportive

7. You can confide in or talk to your family about your problems with having CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when you confide in or talk to them about your problems with having CF?

Not supportive / A little supportive / Supportive / Very supportive

8. Your really want advice from your family about CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they give you advice about CF?

Not supportive / A little supportive / Supportive / Very supportive

9. You share your most private worries and fears about having CF with your family.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when you share your most private worries and fears about having CF with them?

Not supportive / A little supportive / Supportive / Very supportive

10. You turn to your family for suggestions about how to deal with problems related to CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when you turn to them for suggestions about how to deal with problems related to CF?

Not supportive / A little supportive / Supportive / Very supportive
11. Your family understand your problems related to having CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they understand your problems related to having CF?
Not supportive / A little supportive / Supportive / Very supportive

12. Your family helps you if you were stuck in bed because of your CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they help you when you are stuck in bed because of your CF?
Not supportive / A little supportive / Supportive / Very supportive

13. Your family can take you to the doctor if you needed to go because of your CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they take you to the doctor if you need to go because of your CF?
Not supportive / A little supportive / Supportive / Very supportive

14. Your family makes you your meals if you were unable to do it yourself because of your CF?

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they make your meals because you are unable to due to CF?
Not supportive / A little supportive / Supportive / Very supportive

15. Your family helps you with daily chores if you were sick because of your CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they help you with your daily chores if you were sick because of your CF?
Not supportive / A little supportive / Supportive / Very supportive

16. Your family shows you love and affection.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time

How supportive is your family when they show you love and affection?
Not supportive / A little supportive / Supportive / Very supportive
17. Your family loves you and makes you feel wanted.

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

   How supportive is your family when they love you and make you feel wanted?

   Not supportive / A little supportive / Supportive / Very supportive

18. Your family hugs you.

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

   How supportive is your family when they hug you?

   Not supportive / A little supportive / Supportive / Very supportive

19. You have a good time with your family.

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

   How supportive is your family when you have a good time with them?

   Not supportive / A little supportive / Supportive / Very supportive

20. You get together with your family for relaxation.

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

   How supportive is your family when you get together with them for relaxation?

   Not supportive / A little supportive / Supportive / Very supportive

21. You do something enjoyable/fun with your family.

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

   How supportive is your family when you do something enjoyable/fun with them?

   Not supportive / A little supportive / Supportive / Very supportive

22. You do things with your family to help you get your mind off of having CF.

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

   How supportive is your family when you do things with them to help you get your mind off of having CF?

   Not supportive / A little supportive / Supportive / Very supportive
APPENDIX H

MOS SOCIAL SUPPORT SURVEY REVISED – FRIENDS VERSION
APPENDIX H

MOS Social Support Survey Revised – Friends Version

People sometimes look to their friends for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you from your friends if you need it within the past month? Circle the answer that best fits:

1. You can count on your friends to listen to you when you need to talk about having CF.
   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time
   How supportive are your friends when you do talk to them about having CF?
   Not supportive / A little supportive / Supportive / Very supportive

2. Your friends give you information to help you understand your CF.
   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time
   How supportive are your friends when they give you information to help you understand your CF?
   Not supportive / A little supportive / Supportive / Very supportive

3. Your friends gives you good advice about your CF.
   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time
   How supportive are your friends when they give you advice about your CF?
   Not supportive / A little supportive / Supportive / Very supportive

4. Your friends encourage you to do a good job of taking care of your CF.*
   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time
   How supportive are your friends when they encourage you to do a good job taking care of your CF?
   Not supportive / A little supportive / Supportive / Very supportive
5. Your friends are available to listen to concerns or worries about your CF care.*
None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they listen to concerns or worries about your CF care?
Not supportive / A little supportive / Supportive / Very supportive

6. Your friends understand when you sometimes make mistakes in taking care of your CF.*
None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they understand you sometimes make mistakes in taking care of your CF?
Not supportive / A little supportive / Supportive / Very supportive

7. You can confide in or talk to your friends about your problems with having CF.
None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when you confide in or talk to them about your problems with having CF?
Not supportive / A little supportive / Supportive / Very supportive

8. Your really want advice from your friends about CF.
None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they give you advice about CF?
Not supportive / A little supportive / Supportive / Very supportive

9. You share your most private worries and fears about having CF with your friends.
None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when you share your most private worries and fears about having CF with them?
Not supportive / A little supportive / Supportive / Very supportive

10. You turn to your friends for suggestions about how to deal with problems related to CF.
None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when you turn to them for suggestions about how to deal with problems related to CF?
11. Your friends understand your problems related to having CF.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they understand your problems related to having CF?

Not supportive / A little supportive / Supportive / Very supportive

12. Your friends help you if you were stuck in bed because of your CF.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they help you when you are stuck in bed because of your CF?

Not supportive / A little supportive / Supportive / Very supportive

13. Your friends can take you to the doctor if you needed to go because of your CF.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they take you to the doctor if you need to go because of your CF?

Not supportive / A little supportive / Supportive / Very supportive

14. Your friends make you your meals if you were unable to do it yourself because of your CF?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they make your meals because you are unable to due to CF?

Not supportive / A little supportive / Supportive / Very supportive

15. Your friends helps you with daily chores if you were sick because of your CF.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they help you with your daily chores if you were sick because of your CF?

Not supportive / A little supportive / Supportive / Very supportive
16. Your friends show you love and affection.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they show you love and affection?
Not supportive / A little supportive / Supportive / Very supportive

17. Your friends love you and make you feel wanted.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they love you and make you feel wanted?
Not supportive / A little supportive / Supportive / Very supportive

18. Your friends hug you.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when they hug you?
Not supportive / A little supportive / Supportive / Very supportive

19. You have a good time with your friends.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when you have a good time with them?
Not supportive / A little supportive / Supportive / Very supportive

20. You get together with your friends for relaxation.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when you get together with them for relaxation?
Not supportive / A little supportive / Supportive / Very supportive

21. You do something enjoyable / fun with your friends.

None of the time / A little of the time / Some of the time / Most of the time / All of the time

How supportive are your friends when you do something enjoyable / fun with them?
Not supportive / A little supportive / Supportive / Very supportive
22. You do things with your friends to help you get your mind off of having CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time

How supportive are your friends when you do things with them to help you get your mind off of having CF?

Not supportive / A little supportive / Supportive / Very supportive
APPENDIX I

MOS SOCIAL SUPPORT SURVEY REVISED – SOCIAL NETWORK VERSION
APPENDIX I

MOS Social Support Survey Revised – Social Network Version

People sometimes look to online peers with Cystic Fibrosis for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you from online peers with Cystic Fibrosis if you need it within the past month? Circle the answer that best fits.

1. You can count on your online peers with CF to listen to you when you need to talk about having CF.
   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A
   How supportive are your online peers with CF when you do talk to them about having CF?
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

2. Online peers with CF give you information to help you understand your CF.
   None of the time / A little of the time/Some of the time/ Most of the time/ All of the time/ N/A
   How supportive are your online peers with CF when they give you information to help you understand your CF?
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

3. Online peers with CF give you good advice about your CF.
   None of the time / A little of the time/Some of the time/ Most of the time/ All of the time/ N/A
   How supportive are your online peers with CF when they give you advice about your CF?
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

4. Online peers with CF encourage you to do a good job of taking care of your CF.*
   None of the time / A little of the time/Some of the time/ Most of the time/ All of the time/ N/A
   How supportive are your online peers with CF when they encourage you to do a good job taking care of your CF?
   Not supportive / A little supportive / Supportive / Very supportive/ N/A
5. **Online peers with CF are available to listen to concerns or worries about your CF care.***

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

   **How supportive are your online peers with CF when listen to concerns or worries about your CF care?**
   
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

6. **Online peers with CF understand when you sometimes make mistakes in taking care of your CF.***

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

   **How supportive are your online peers with CF when they understand you sometimes make mistakes in taking care of your CF?**
   
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

7. **You can confide in or talk to your online peers with CF about your problems with having CF.**

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

   **How supportive are your online peers with CF when you confide in or talk to them about your problems with having CF?**
   
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

8. **Your really want advice from your online peers with CF about CF.**

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

   **How supportive are your online peers with CF when they give you advice about CF?**
   
   Not supportive / A little supportive / Supportive / Very supportive/ N/A

9. **You share your most private worries and fears about having CF with your online peers who also have CF.**

   None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

   **How supportive are your online peers with CF when you share your most private worries and fears about having CF with them?**
   
   Not supportive / A little supportive / Supportive / Very supportive/ N/A
10. You turn to online peers with CF for suggestions about how to deal with problems related to CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when you turn to them for suggestions about how to deal with problems related to CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

11. Online peers with CF understand your problems related to having CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they understand your problems related to having CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

12. Online peers with CF help you if you were stuck in bed because of your CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they help you when you are stuck in bed because of your CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

13. Online peers with CF can take you to the doctor if you needed to go because of your CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they take you to the doctor if you need to go because of your CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

14. Online peers with CF make you your meals if you were unable to do it yourself because of your CF?

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they make your meals because you are unable to due to CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A
15. Online peers with CF help you with daily chores if you were sick because of your CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they help you with your daily chores if you were sick because of your CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

16. Online peers with CF show you love and affection.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they show you love and affection?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

17. Online peers with CF love you and makes you feel wanted.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they love you and make you feel wanted?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

18. Online peers with CF hug you.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when they hug you?

Not supportive / A little supportive / Supportive / Very supportive N/A

19. You have a good time with your online peers with CF.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when you have a good time with them?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

20. You get together with your online peers with CF for relaxation.

None of the time / A little of the time/ Some of the time/ Most of the time/ All of the time/ N/A
How supportive are your online peers with CF when you get together with them for relaxation?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

21. You do something enjoyable/fun with your online peers with CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when you do something enjoyable/fun with them?

Not supportive / A little supportive / Supportive / Very supportive/ N/A

22. You do things with your online peers with CF to help you get your mind off of having CF.

None of the time / A little of the time/Some of the time/ Most of the time/ All of the time/ N/A

How supportive are your online peers with CF when you do things with them to help you get your mind off of having CF?

Not supportive / A little supportive / Supportive / Very supportive/ N/A
APPENDIX J

Infection Control Adherence Scale – Patient Version

Question A: Do you have Pseudomonas Aeruginosa or Burkholderia Cepacia or any other Multi-Drug Resistant Infection?

   YES       NO

Question B: Do you have regular physical contact with a friend with CF?

   YES       NO

   If no, have you had regular physical contact with a friend with CF in the past?

   YES       NO

Question C: Do you have a sibling(s) with CF?

   YES       NO

Question D: Do you have a history of attending summer camps with other patients with CF?

   YES       NO

Question E: Do you actively avoid contact with other CF patients?

   YES       NO
APPENDIX K

INFECTION CONTROL ADHERENCE SCALE – PARENT VERSION
APPENDIX K

Infection Control Adherence Scale – Parent Version

Question A: Does your child have Pseudomonas Aeruginosa or Burkholderia Cepacia or any other Multi-Drug Resistant Infection?
   YES      NO

Question B: Does your child have regular physical contact with another individual with CF (i.e., friend, sibling, or other relative?)
   YES      NO

If no, has your child had regular physical contact with a friend with CF in the past?
   YES      NO

Question C: Does your child have a sibling(s) with CF?
   YES      NO

Question D: Does your child have a history of attending summer camps with other patients with CF?
   YES      NO

Question E: Does your actively avoid contact with other CF patients?
   YES      NO
APPENDIX L

SELF CARE INVENTORY - CYSTIC FIBROSIS (PARENT VERSION)
APPENDIX L

Self Care Inventory - Cystic Fibrosis (Parent Version)

The following questions relate to your child’s CF treatments and how closely he/she adheres to the recommendations of the CF team within the past two weeks:

<table>
<thead>
<tr>
<th></th>
<th>1 Never do as recommended</th>
<th>2 Rarely do as recommended</th>
<th>3 Sometimes do as recommended</th>
<th>4 Usually do as recommended</th>
<th>5 Always do as recommended</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airway Clearance</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Aerosol Medication</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Metered Dose Inhalers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Oral Antibiotics</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Inhaled Antibiotics (eg, TOBI)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Pancreatic Enzymes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Nutritional Supplements (eg, Carnation Instant Breakfast)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Vitamins</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
</tbody>
</table>
APPENDIX M

Self Care Inventory - Cystic Fibrosis (Patient Version)
APPENDIX M

Self Care Inventory - Cystic Fibrosis (Patient Version)

The following questions relate to your CF treatments and how closely you adhere to the recommendations of the CF team within the past two weeks:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airway Clearance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aerosol Medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metered Dose Inhalers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral Antibiotics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inhaled Antibiotics (eg, TOBI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreatic Enzymes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutritional Supplements (eg, Carnation Instant Breakfast)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamins</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
APPENDIX N

Relevant Descriptive, Chi-square, and T-test Tables
APPENDIX N

Relevant Descriptive, Chi-square, and T-test Tables

Table N1. Descriptive Statistics for Study Variables (N = 57)

<table>
<thead>
<tr>
<th>Variable</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Perceived Social Support</td>
<td>3.36 (.67)</td>
</tr>
<tr>
<td>Perceived Friend Social Support</td>
<td>3.21 (.79)</td>
</tr>
<tr>
<td>Perceived Family Social Support</td>
<td>3.60 (.95)</td>
</tr>
<tr>
<td>Perceived Social Network Support</td>
<td>3.12 (.79)</td>
</tr>
<tr>
<td>Emotional/Informational Support</td>
<td>3.26 (.73)</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>3.14 (.72)</td>
</tr>
<tr>
<td>Overall CF Disease Knowledge</td>
<td>56.50 (24.25)</td>
</tr>
<tr>
<td>Self-Reported Medical Adherence</td>
<td>4.14 (.87)</td>
</tr>
</tbody>
</table>

*Note.* SD = Standard Deviation. Social Support variables range from 1 (None of the time) to 5 (All of the time). CF Disease Knowledge is scored on a 100 point scale. Social Networking Use and CF Specific Social Networking Use ranges from 1 (Everyday) to 5 (Less than once per month). Medical Adherence ranges from 1 (Never do as recommended) to 5 (Always do as recommended)
### Table N2. Chi-square Analyses Comparing Reported IC Adherent Participants v. Reported IC Nonadherent Participants on Relevant IC Adherence Variables (N = 57)

<table>
<thead>
<tr>
<th>Variable</th>
<th>df</th>
<th>$\chi^2$</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a Multi-Drug Resistant Infection?</td>
<td>1</td>
<td>17.06</td>
<td>.000**</td>
</tr>
<tr>
<td>Do you have regular contact with CF patients?</td>
<td>1</td>
<td>17.50</td>
<td>.000**</td>
</tr>
<tr>
<td>Do you have a sibling diagnosed with CF?</td>
<td>1</td>
<td>3.80</td>
<td>.05</td>
</tr>
<tr>
<td>Do you actively avoid CF patients?</td>
<td>1</td>
<td>25.65</td>
<td>.000**</td>
</tr>
</tbody>
</table>

** Denotes significance

### Table N3. Chi-square Analyses Comparing Participants With a Sibling Diagnosed with CF v. Participants Without a Sibling Diagnosed with CF on Relevant Outcome Variables (N = 57)

<table>
<thead>
<tr>
<th>Variable</th>
<th>df</th>
<th>$\chi^2$</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a Multi-Drug Resistant Infection?</td>
<td>1</td>
<td>22.61</td>
<td>.000**</td>
</tr>
<tr>
<td>Do you have regular contact with CF patients?</td>
<td>1</td>
<td>17.23</td>
<td>.000**</td>
</tr>
<tr>
<td>Do you actively avoid CF patients?</td>
<td>1</td>
<td>.59</td>
<td>.44</td>
</tr>
<tr>
<td>Do you have a social networking account?</td>
<td>1</td>
<td>.01</td>
<td>.95</td>
</tr>
<tr>
<td>Do you have a CF specific social networking account?</td>
<td>1</td>
<td>2.41</td>
<td>.12</td>
</tr>
</tbody>
</table>

** Denotes significance
Table N4. *t*-test Results Comparing Participants With a Sibling Diagnosed with CF v. Participants Without a Sibling Diagnosed with CF on Relevant Outcome Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sibling with CF</th>
<th>No Sibling with CF</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Overall Social Support</td>
<td>3.14</td>
<td>.65</td>
<td>3.30</td>
</tr>
<tr>
<td>Friend Social Support</td>
<td>3.19</td>
<td>.67</td>
<td>3.29</td>
</tr>
<tr>
<td>Family Social Support</td>
<td>2.89</td>
<td>.65</td>
<td>3.65</td>
</tr>
<tr>
<td>Social Network Support</td>
<td>3.33</td>
<td>.77</td>
<td>2.90</td>
</tr>
<tr>
<td>Emotional/Informational Support</td>
<td>3.08</td>
<td>.64</td>
<td>3.36</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>3.14</td>
<td>.76</td>
<td>3.07</td>
</tr>
<tr>
<td>CF Disease Knowledge</td>
<td>32.64</td>
<td>9.06</td>
<td>65.74</td>
</tr>
<tr>
<td>Social Network Account Use</td>
<td>2.00</td>
<td>1.24</td>
<td>2.96</td>
</tr>
<tr>
<td>CF Specific Social Networking Use</td>
<td>2.68</td>
<td>1.55</td>
<td>3.55</td>
</tr>
<tr>
<td>Medical Adherence</td>
<td>3.93</td>
<td>.99</td>
<td>4.27</td>
</tr>
</tbody>
</table>

*Note.* SD = Standard Deviation. Social Support variables range from 1 (None of the time) to 5 (All of the time). CF Disease Knowledge is scored on a 100 point scale. Social Networking Use and CF Specific Social Networking Use ranges from 1 (Everyday) to 5 (Less than once per month). Medical Adherence ranges from 1 (Never do as recommended) to 5 (Always do as recommended)

*p<.05, **p<.01
Table N5.Chi-square Analyses Comparing Participants With a CF Specific Social Networking Account and Participants Without a CF Specific Social Networking Account on Relevant IC Outcome

<table>
<thead>
<tr>
<th>Variable</th>
<th>df</th>
<th>( \chi^2 )</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a Multi-Drug Resistant Infection?</td>
<td>1</td>
<td>3.99</td>
<td>.046**</td>
</tr>
<tr>
<td>Do you have regular contact with CF patients?</td>
<td>1</td>
<td>15.12</td>
<td>.000**</td>
</tr>
<tr>
<td>Do you actively avoid CF patients?</td>
<td>1</td>
<td>.00</td>
<td>.98</td>
</tr>
</tbody>
</table>

** Denotes significance

Variables (N = 57)
Figure N1. Interaction between Overall Perceived Social Support and General CF Disease Knowledge (N= 57)
Table N6. *t*-test Results Comparing Participants With a CF Specific Social Networking Account and Participants Without a CF Specific Social Networking Account on Relevant Outcome Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>With CF Social Networking Account</th>
<th>Without CF Social Networking Account</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Social Support</td>
<td>3.28 (.67)</td>
<td>3.14 (.74)</td>
<td>-.57</td>
</tr>
<tr>
<td>Friend Social Support</td>
<td>3.30 (.78)</td>
<td>3.16 (.73)</td>
<td>-.51</td>
</tr>
<tr>
<td>Family Social Support</td>
<td>3.20 (.88)</td>
<td>3.76 (1.05)</td>
<td>1.70</td>
</tr>
<tr>
<td>Social Network Support</td>
<td>3.29 (.62)</td>
<td>2.51 (1.01)</td>
<td>-2.90</td>
</tr>
<tr>
<td>Emotional/Informational Support</td>
<td>3.26 (.74)</td>
<td>3.25 (.74)</td>
<td>-.05</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>3.16 (.69)</td>
<td>2.93 (.85)</td>
<td>-.86</td>
</tr>
<tr>
<td>CF Disease Knowledge</td>
<td>47.65 (24.77)</td>
<td>66.36 (17.15)</td>
<td>2.64*</td>
</tr>
<tr>
<td>Social Network Account Use</td>
<td>1.38 (.50)</td>
<td>1.54 (.82)</td>
<td>-.74</td>
</tr>
<tr>
<td>Medical Adherence</td>
<td>4.11 (.94)</td>
<td>4.10 (1.10)</td>
<td>-.13</td>
</tr>
</tbody>
</table>

*Note.* SD = Standard Deviation. Social Support variables range from 1 (None of the time) to 5 (All of the time). CF Disease Knowledge is scored on a 100 point scale. Social Networking Use ranges from 1 (Everyday) to 5 (Less than once per month). Medical Adherence ranges from 1 (Never do as recommended) to 5 (Always do as recommended)

*p<.05
APPENDIX O

Significant Correlation Coefficients among Relevant Study Variables
# APPENDIX O

## Significant Correlation Coefficients among Relevant Study Variables

<table>
<thead>
<tr>
<th>Variables</th>
<th>Correlated Variables</th>
<th>(Correlation and Significance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Age</td>
<td>CF Social Network Account = .520 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount of usage of CF Social Network Account = .521 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Family Social Support = -.287 ( p = .031 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Friends Social Support = .387 ( p = .004 )</td>
<td></td>
</tr>
<tr>
<td>Amount of Internet Usage</td>
<td>CF Social Network Account = .287 ( p = .030 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount of usage of CF Social Network Account = .269 ( p = .043 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>IC Adherence = .303 ( p = .022 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Family Social Support = .397 ( p = .002 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Social Support = .281 ( p = .034 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>General CF Disease Knowledge = .520 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Emotional/Informational Support = .320 ( p = .039 )</td>
<td></td>
</tr>
<tr>
<td>CF Social Network Account</td>
<td>Amount of usage of CF Social Network Account = .854 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Family Social Support = .420 ( p = .001 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Social Network Support = .393 ( p = .010 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>General CF Disease Knowledge = .483 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Emotional/Informational Support = .320 ( p = .039 )</td>
<td></td>
</tr>
<tr>
<td>Amount of usage of CF Social Network Account</td>
<td>Overall Perceived Family Social Support = .434 ( p = .001 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Social Network Support = .315 ( p = .042 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>General CF Disease Knowledge = .473 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td>IC Adherence</td>
<td>Amount of Internet Usage = .303 ( p = .030 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount of usage of CF Social Network Account = .277 ( p = .038 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Medical Adherence = .268 ( p = .044 )</td>
<td></td>
</tr>
<tr>
<td>Medical Adherence</td>
<td>IC Adherence = .268 ( p = .044 )</td>
<td></td>
</tr>
<tr>
<td>General CF Disease Knowledge</td>
<td>Amount of Internet Usage = .520 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CF Social Network Account = .483 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount of usage of CF Social Network Account = .473 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Family Social Support = .636 ( p = .000 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall Perceived Emotional/Informational Support = .465 ( p = .002 )</td>
<td></td>
</tr>
</tbody>
</table>