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# The Development and Impact of an Online Social Networking Community for Adolescents with Cystic Fibrosis

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UNIVERSITY OF MIAMI

THE DEVELOPMENT AND IMPACT OF AN ONLINE SOCIAL NETWORKING  
COMMUNITY FOR ADOLESCENTS WITH CYSTIC FIBROSIS

By

Sandy Liliana Romero

A DISSERTATION

Submitted to the Faculty  
of the University of Miami  
in partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

Coral Gables, Florida

May 2013

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THE DEVELOPMENT AND IMPACT OF AN ONLINE SOCIAL NETWORKING  
COMMUNITY FOR ADOLESCENTS WITH CYSTIC FIBROSIS

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The Development and Impact of an Online Social  
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This is the first qualitative study to examine the social support functions of a social networking website for adolescents with Cystic Fibrosis (CF) over an academic year. Patients with CF are segregated and not allowed to meet face-to-face; this networking site was evaluated as an alternative for providing peer support. Age and gender differences in website usage were examined in participants enrolled in the CFfone™ study. Thematic analyses were used to examine the provision of four types of social support: companionship, emotional, informational, and instrumental, in relation to topics raised on the website. Results suggested that adolescents used the website most often to provide companionship support in relation to typical adolescent issues, such as school and pop culture. Gender and age differences were found in the frequency and function of website usage; however, the topics of discussion (non CF-related vs. CF-related) did not differ. Clinical implications and directions for future research on the use of social networking websites for adolescents with chronic illnesses are discussed.

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## Chapter1: Introduction

Cystic Fibrosis (CF), the most common, life-shortening genetic disease found among Caucasian populations, affecting approximately 30,000 individuals in the United States, with approximately 50% of patients under the age of 18 (Cystic Fibrosis Foundation [CFF], 2011). CF is a progressive, multisystem disease, affecting primarily the lungs, pancreas, and digestive systems. It is caused by a recessive gene, with over 1800 genetic mutations identified to date (Cystic Fibrosis Mutation Database, 2012). Treatment for CF is burdensome, requiring multiple medications and treatments which can take two to four hours each day (Eakin, Bilderback, Boyle, Mogayzel, Riekert, 2011). In addition, CF is a deteriorating, chronic condition; patients experience recurrent pulmonary exacerbations, which require frequent, lengthy hospitalizations. Thus, management of CF affects health-related quality of life across many domains of functioning (Barker & Quittner, 2010; Glasscoe & Quittner, 2008;).

Over the past 20 years, remarkable medical advancements have been made in treating CF (e.g., universal newborn screening, aggressive use of antibiotics, mucolytics, and nutritional interventions), extending the median age of survival for patients with CF to 36.8 years—about a six year increase from 2000 (CFF, 2011). Increased survival may also be attributed to rigid infection control procedures introduced in 2003, which prohibit physical contact among CF patients (Saiman & Siegel, 2003). As a consequence, the opportunity to interact with others who have CF has been severely limited, leading to the potential for social isolation. These guidelines have eliminated most types of contact with other patients with CF, such as sharing hospital rooms, attending CF camps, riding in the same car, dancing or hugging, or participating in support groups (Saiman, 2011). To our

knowledge, this is the first study to examine the effects of social support on patients with CF following implementation of these guidelines.

In addition to managing the medical challenges of CF, adolescents also face difficulties in accomplishing typical developmental goals, such as increased independence, spending time with peers, and developing romantic relationships (Barker & Quittner, 2010). Prior studies in children and adolescents with other chronic illnesses have shown that they often feel “different” from their peers and report greater isolation and loneliness (Conway 1996; Yeo & Sawyer, 2005). They feel different from their healthy peers because they take medications, cope with negative sides effects (e.g., fatigue), are less able to participate in social and recreational activities, and may fall behind academically because of frequent school absences (Quittner, Romero, Kimberg, Blackwell, & Cruz, 2011). These social challenges are more extreme for adolescents with CF because they are prohibited from interacting with others who have the same illness, and thus, are not able to access this type of peer support.

The current study utilized social networking technology to provide peer support to adolescents with CF using an online support community. This is the first study to examine the provision of social support during online exchanges for individuals with CF. Additionally, the issues that were discussed and elicited peer support on the social networking site (SNS) were examined.

### **Social Support**

Several decades of research have shown that social support is directly and indirectly linked to better psychological and physical health in both adults and children with a chronic illness (Glasgow, Barrera, McKay, & Boles, 1999; Hudson, Lee,

Miramontes, Portillo, 2001; Shepanski et al., 2005; Varni, Babani, Wallander, Roe, & Frasier, 1989). Conversely, negative outcomes (behavior problems, depression, increased morbidity and mortality) have been related to both a lack of social support and the provision of negative types of support (Berkman, 1995; Brummet et al., 2001; Herzer, Umfress, Aljadeff, Ghai, Zakowski, 2009). In terms of the definition and measurement of social support, despite a voluminous literature, there is little consensus on the concepts and dimensions that make up this construct (Berkman, Glass, Brissette, & Seeman, 2000; Stephens, Alpass, Tower, & Stevenson, 2011; Williams, Barclay, & Schmied, 2004). The most widely accepted definitions are discussed below.

**Models and Dimensions of Social Support.** In an effort to identify the mechanisms by which social support exerts its effects, several different models have been proposed (Barrera, 1986; Cohen, 2004; Gottlieb & Bergen, 2010). Two major models have garnered the most support in the literature: 1) the main effects model (a direct effect), and 2) the buffering model (moderating effects) (Cohen, 2004; Cohen & Wills, 1985; Quittner, Glueckauf, & Jackson, 1990). The main effects model suggests that social support leads to positive outcomes across all levels of stress. In contrast, the buffering model indicates that social support is associated with positive outcomes only when stress is high; social support is not expected to lead to positive effects for those reporting low levels of stress. Thus, according to the buffering model, social support is protective for an individual experiencing high levels of stress. There is support for both models (see Cohen & Wills 1985). However, most studies appear to support the use of the direct effects model when stress is chronic (Quittner et al., 1990; Revenson, 1993) and the buffering model when stress is acute (Lepore, Evans, & Schneider, 1991;

Williams et al., 2004). Thus, this study hypothesized that the direct effects model is most appropriate given the chronic and varying levels of stress associated with CF.

In addition, two primary dimensions of social support have been identified: structural and functional (Cohen, 2004; Cohen & Wills, 1985). Structural support (also called social integration) refers to the characteristics of an individual's social network, including the number of people, relationship dynamics or connectedness, and the density of the network. It was first assumed that the number of people in the network was critical in determining psychological outcomes; larger social networks were thought to lead to better outcomes (Tolsdorf, 1976; Wilcox, 1981). However, evidence has shown that individuals with larger social networks do not necessarily have better perceptions of support (i.e., less loneliness) than those with smaller networks (Segrin & Passalacqua, 2010).

Research has also shown that size of the network is not an indicator of how much support a person is receiving. Children with chronic illnesses and their parents often report having smaller social networks than families of healthy children, but the amount of perceived support was the same for both types of families (Benson, Gross, Messer, Kellum, & Passmore, 1991; Quittner, 1992). Perceived support appears to be an important indicator of whether support is beneficial or not. It is subjective and relies on the recipient's judgment of the effectiveness and availability of support. In contrast, received support is objective and includes the type and amount of support that is received (Barrera, 1986; Uchino, 2009). Current literature suggests that perceived, rather than

received, support has been most closely linked to positive psychological, emotional, and physical outcomes (Cohen, 2004; Gottlieb & Bergen, 2010; Uchino 2009; Quittner et al., 1990).

Functional support reflects the different types of support that are provided. Different typologies of support with different number of categories have been proposed. The four most common types of functional support are: emotional, informational, instrumental, and companionship (Barrera 1986; Cohen & Wills, 1985; Gottlieb & Bergen, 2010).

These are the types of support that were evaluated in this study. Emotional support refers to perceptions of being cared for and loved. Informational support (also referred to as cognitive support) provides helpful information or problem-solving ideas. Instrumental support (also known as tangible support) is related to the provision of material aid and resources (e.g. picking up medications from the pharmacy) or receipt of a service (e.g., a ride to the doctor's appointment). Companionship support involves spending time with others and a sense of belongingness. Different types of support tend to differ in their effects. Emotional and informational support tend to be effective in many stressful contexts (e.g., during times of sadness, stress, or a decline in health), whereas, instrumental and companionship support are only effective in specific situations (e.g., financial difficulty, a loss of companion). However, types of support do not appear to be independent of each other; people who receive companionship support also tend to also receive emotional and instrumental support (Cohen, 2004).

Different types of functional support are also linked to different support providers (e.g. parent, sibling, healthcare provider). Graetz, Shute, and Sawyer (2000) found that parents provided more tangible, instrumental support than peers to adolescents with CF,

and peers provided more emotional support than parents. Similar results were found in adolescents with diabetes (La Greca et al, 1995; La Greca, Bearman, & Moore, 2002).

Furthermore, social support seems to be context specific; it varies across different populations (e.g., age, gender, ethnicity) and stressful contexts (e.g., time of diagnosis vs. chronic phase of adaptation). To test the effects of social support, researchers have concluded that the population, sources of stress, and types of support must be well-defined (Cohen, 2004; Williams et al., 2004). For example, Helgeson and colleagues (2006) examined friendship and the types of social support received by three different adolescent groups: girls with diabetes, boys with diabetes, and those without diabetes. They found a difference in the quantity and function of peer support for adolescents with and without diabetes. Both girls and boys with diabetes reported having more friends than adolescents without diabetes. Emotional support from friends was also more important to girls than boys across diabetes and healthy groups. Based on these findings, it appears that both the amount and function of support differs between those with and without a chronic illness and between genders. The current study examined online social support in adolescents who varied by age and sex; all had a CF.

**Social Support in Adolescents.** Social support for adolescents is not dependent on one source, but rather consists of a network of people and different types of social interactions (e.g. social media). Within the psychological literature, the ecological perspective proposed by Bronfenbrenner (1979; Perry, Kelder, & Komro, 1993) provides a comprehensive model of how various systems affect development. This model is composed of several social systems (e.g. microsystem, mesosystem, exosystem, and macrosystem) which surround the adolescent, with interactive effects among these

systems and the individual. For adolescents with chronic illnesses, their social networks include parents, siblings, and peers who comprise the immediate circle, followed by doctors, nurses, and therapists with whom the adolescent interacts during clinic visits and hospitalizations. In the exosystem, health organizations and foundations may also have an effect on an adolescent's medical care and treatments (e.g., testing new drugs). For example, one study evaluated the social networks of adolescents (ages 13 to 17) with a chronic illness (asthma, epilepsy, arthritis, and diabetes) and identified six main categories of support: parents, peers, health care providers, school, technology, and pets (Kyngäs, 2004).

Research has found that different types of support (emotional, informational, instrumental, companionship) can be provided by a variety of sources in the adolescent's network. The health care team tends to provide informational support that facilitates an understanding of the disease and its treatments, however, members of the medical team tend not to be relied on for emotional support (Dunsmore & Quine, 1995). Peers provide emotional and companionship support by sharing similar experiences, while parents tend to provide instrumental support by taking the adolescent to clinic visits (Graetz et al., 2000; La Greca, 1992; La Greca & Thompson, 1998). Note that this division of resources is not constant throughout development. Research has found that functional support is dynamic across development and shifts with developmental demands (Vaux, 1985). For example, younger adolescents rely on their parents for emotional support, but as they get older and seek greater independence from their parents, their need for emotional support shifts to their peers (Kuttler, La Greca, & Prinstein, 1993). Parents are then relied on more for instrumental support (La Greca, 1992; Graetz et al., 2000).

Not only do adolescents have more peers than family members in their social network (twice as many; Frey & Rothlisberger, 1996; Furman & Buhrmester, 1992), but peers tend to have more of a prominent effect on adolescents' lives than parents. This can result in either positive (e.g. high self-esteem, psychological well-being) or negative outcomes (engaging in disruptive behaviors, poor adherence to treatment regimen; Del Valle, Bravo, & Lopez, 2010; Klineberg et al., 2006). For example, Herzer and colleagues (2009) reported that peer support mediated the effects associated with the poor quality of the relationship between teens and parents across several chronic illnesses (ages 11 to 18 years). However, the opposite was not found. Parent support did not mediate the negative effects of poor peer relationships (Herzer et al., 2009). This indicates what an important role peer support plays in the lives of adolescents with a chronic illness. Thus, this study focused exclusively on peer-to-peer support.

In addition to changes in social support over time (e.g. larger networks, shift of functions), research has also revealed differences by gender. The effect of social support as a stress buffer has been found to be greater for girls than boys (Piko, 1998). In addition, differences in structural support have found that girls receive and provide more support than boys. This may explain the consistent findings showing that peer relationships are more supportive for girls than boys (Colarossi & Eccles 2003; Helgeson, Reynolds, Escobar, Siminerio & Becker, 2007; Kuttler et al., 1993). Differences have also been shown for functional support in the presence of stress; girls tend to receive emotional and informational support, whereas boys tend to receive instrumental support (Piko, 1998). Although gender differences have been found, it is not known what role

technology may play in the provision and receipt of social support across age and gender. The current study examined support exchanges, taking these demographic variables into account.

**Peer Support.** Evidence on whether social support has positive effects on the psychological well-being of adolescents with a chronic illness is not clear. On the one hand, a cross-sectional study reported that peer support was positively related to disease-specific quality of life (e.g. acceptance of diabetes) in adolescents with diabetes (La Greca & Bearman, 2002). Further, Skinner, John, and Hampson (2000) found both peer and family support predicted better psychological well-being (e.g. depression and overall well-being) 6 months later in adolescents (12 -18 years) with diabetes. Similarly, Wallander and Varni (1989) found that both family and peer support were negatively correlated with externalizing and internalizing behavior problems in youths (ages 4 to 16) across a variety of chronic diseases (e.g. diabetes, spina bifida). Another study found peer support to be related to fewer symptoms of depression in a population of adolescents with HIV (Abramowitz et al., 2009).

However, several studies have not found these positive effects. A recent longitudinal study reported that peer support was only marginally related to better psychological health (e.g. depression, anxiety, social competence) in adolescents with diabetes at baseline, with no relationship found one year later (Helgeson et al., 2007). Graetz, Shute, and Sawyer (2000) also found no associations between peer support and internalizing and externalizing behaviors in adolescents with CF. One possible reason for these inconsistent results may be the inconsistent definitions used for “peer” or “friend” support. Peer is a general term that includes schoolmates, classmates, neighborhood

friends, best friends, siblings, acquaintances, etc. It is a broad term and does not adequately reflect the closeness of the peer or the peer's awareness of the adolescent's chronic illness. The definition of peers for the purpose of this study is those who share the same illness. The current study specifically examined the support provided by users who belonged to a social network site specifically for adolescents with CF.

Similar to the findings on psychological well-being, the beneficial evidence of peer support on disease management also appear inconclusive. Skinner et al., (2000) found both peer and family support predicted dietary self-care six months later in teens with diabetes. La Greca and Bearman (2002) also examined the effect of peer support in conjunction with parental support on disease management in adolescents with diabetes. They found that companionship support from peers was more beneficial for disease management and treatment adherence than companionship support provided by parents. Bearman and La Greca (2002) also found that disease-specific support provided by friends (ages 11 to 18 years; n = 74) predicted adherence to specific diabetes care (e.g. blood glucose testing), but not the overall composite adherence score. They also found that friends were perceived to be most supportive during emotional exchanges, exercise, and blood glucose testing.

In contrast, some studies have found no relationship between peer support and disease management. Helgeson and colleagues (2007) found no association between peer support, self-care, and diabetes control in adolescents with diabetes at baseline or one year later. A more recent study reported similar, null findings (Carcone, Ellis, Weisz, & Naar-King, 2011). Kygnas and colleagues investigated the effect of friend support on adherence across various chronic illnesses, including diabetes, and they also found mixed

results. They reported that friend support was related to adherence in adolescents with epilepsy and diabetes (Kyngas, 2000a; Kyngas, 2000b), but not in adolescents with asthma, epilepsy, and juvenile rheumatoid arthritis (JRA; Kyngas, 1999; Kyngas, 2001; Kyngas, 2002). However, friend support was a significant predictor of adherence when these different populations were combined in a later analysis (Kyngas & Rissanen, 2001). This may be misleading because, as mentioned above, not all studies supported the relationship between friend support and adherence. Thus, it is better to evaluate the effects of peer support on disease groups separately, so that researchers can be certain the effects occurred in relation to the demands of that specific illness. This study focused on the effects of peer support in the context of adolescents managing CF.

Another reason for the lack of consistency in the results of peer support in the context of disease management is the broad definition of “friend” that is often used. Even when researchers categorized peer support into classmate and friend support, the results were still conclusive. Some researchers found that classmate support had a greater effect on psychological adjustment than friend support (Varni, Katz, Colegrove, & Dolgin, 1994; Varni, Setoguchi, Rappaport, & Talbot, 1992; Von Weiss et al., 2002), whereas other studies found friend support to be more effective than classmate support (Trask et al., 2003).

A key part of the definition of “peer,” “friend,” or “classmate” support that has not been clear is whether the support provider is aware of the diagnosis. No studies to date have asked whether the “friend” or “classmate” knows about the adolescent’s diagnosis. Unfortunately, many adolescents may not be comfortable telling their friends about their health condition. Cohen, Franco, Motlow, Reznik, and Ozuah (2003) found that only

39% of asthmatic teens disclosed their illness to friends. Those who did not disclose tended to be embarrassed about their illness and its treatments. Furthermore, they found that those who were embarrassed about their asthma were less likely to carry and use their medications in front of friends.

Thus, knowledge of the adolescent's disease is likely to affect the types of support that are provided and without this awareness, it is unlikely that support which facilitates treatment adherence or any other disease related issues will be provided (Modi, Quittner, & Boyle, 2010; Greco, Pendley, McDonnell, & Reeves, 2001). In fact, lack of disclosure can become another source of stress when interacting with peers (Berlin, Sass, Davies, Jandrisevits, & Hains, 2005).which can be an explanation to Hains et al.'s (2007) finding. They reported that friend support was a moderator for diabetes stress and metabolic rate, however, the direction of the effect was the opposite of what they expected. Teens with high levels of friend support tended to experience greater diabetes stress, which was associated with a worse metabolic rate. This was most likely due to the fact that the majority of the adolescents' friends did not know about their illness; thus, stress may have been related to concealing their illness, which may have affected adherence to their medications, leading to worse health outcome (e.g. metabolic rate). Unfortunately, this study did not specify which type of "friend" the adolescent was considering when rating their support.

Another study, which asked adolescents with multiple sclerosis about whether peers knew about their diagnosis and why they had not taken their medications found that almost half of the adolescents stopped their treatment after 20 months (47%) because they were experiencing internal and external "medication-peer-tug-of-war"

(Thannhauser, Mah, & Metz, 2009). Adolescents wanted to be adherent to their regimen, but at the same time, did not want to be different from their peers. This mainly occurred when peers did not know about the diagnosis. Although peer support was not measured, this study provided evidence on how the peer's knowledge of the disease affects how teens with chronic conditions think and behave.

In a recent study of adults with CF, disclosure was related to more positive effects than negative effects in close friends relationships (Modi et al., 2010). Clark and colleagues (1992) found similar, positive effects for a support group. Adolescents with a chronic illness reported better quality of life and adjustment following participation in the support group, suggesting that support from same-age, healthy peers who know about their condition may be important. The researchers concluded that support from healthy peers is beneficial to an adolescent with a chronic illness, once healthy peers understand and are comfortable with the peer's disease. Greco and colleagues (2001) also found that healthy peers who are educated about the illness and its treatments had a positive effect on diabetes care in adolescents.

Social support from same-illness peers has consistently produced positive effects on psychological adjustment and disease management. Examining the effects of peer support in adolescents with the same illness accounts for disclosure because everyone knows they have a specific illness. This may explain why adolescents with a chronic illness perceive peers with the same illness to be more supportive than those without a chronic illness (Blum, 1992; Palmer et al., 2000). Adolescents reported feeling more "normal" with friends who had the same illness (Woodgate, 1998). One oncology camp study found that adolescents with various types of cancer (ages 13 to 18 years) felt more

comfortable with same-illness peers than with their friends at home. Adolescents also reported improved psychosocial outcomes at the end of the camp, including better global self-worth, higher competence in terms of physical appearance and greater social acceptance (Meltzer & Rourke, 2005). Another study found that adolescents who attended a diabetes camp showed improvements in adherence as reported by parents, and better glycemic control seven months later. In contrast, adolescents from a local diabetes clinic who did not attend camp did not show these improvements in glycemic control (Wang, Stewart, Tuli, & White, 2008).

In conclusion, the effects of peer support on psychological well-being and disease management are best detected when disclosure and knowledge of the adolescent's illness is accounted for. Examining social support from peers with the same illness is a way to account for both of these factors. Thus, this study examined the provision and receipt of social support by peers with the same illness on a social networking website for adolescents with CF.

### **Online Social Support**

Internet usage is at its highest for the adolescent age group, with 95% of teens (ages 12 to 17 years) using the internet and 80% of adolescent online users using the internet for social networking purposes, compared to 65% of adults (Lenhart et al., 2011). In comparing internet usage between adolescents with and without a chronic illness, Suris, Akre, Berchtold, Bélanger, and Michaud (2010) found that girls with a chronic illness used the internet significantly more than their peers, whereas no differences in usage were detected for boys. Thus, adolescents use the internet in large numbers, primarily for the purpose of "socialization" (Oprea & Stan, 2012).

This has led to increased interest in examining the effects of online communication on adolescent development. Contrary to earlier concerns about the negative aspects of electronic communication (greater computer use is associated to greater isolation, poorer social skills), current research has found that online communication has positive effects on adolescent development (Baker & White, 2010; Subrahmanyam, Kraut, R., Greenfield, & Gross, 2001). More specifically, online communication has been found to facilitate the formation of friendships, enhance the quality of friendships, and increase adolescents' self-esteem, all of which are necessary for the mastery of tasks, such as development of an identity, social skills and romantic relationships (Peter, Valkenburg, & Schouten, 2006; Valkenburg & Peter, 2011). Research has shown that adolescents prefer communicating via the internet rather than face-to-face. This is because they can express themselves more openly on sensitive and/or embarrassing topics and be more attentive to information that is being communicated since there are no auditory and visual cues present with face-to-face communication, which can be distracting and/or inhibit emotional expression (Letourneau et al., 2012; Valkenburg & Peter, 2011). In addition, controllability is a key feature that attracts adolescents to online communication. Valkenburg and Peter (2011) describe three components of controllability that are unique to online interactions: anonymity, which entails the concealment of identity and physical appearance (e.g. race, weight, color of eyes); asynchronicity, which refers to the opportunity adolescents have to think and edit any comments or responses they want to make before they actually make it; and accessibility, which reflects the freedom adolescents have to talk to whomever they want (whether it be someone they know, someone they haven't spoken to for a long time, or someone they have never met).

In addition to controllability, the convenience and accessibility of online communication that is appealing and possibly even necessary for adolescents with a chronic illness who face physical difficulties and barriers related to their illness. For instance being connected intravenously to medications or being connected to a feeding bag may make moving or traveling to a location in order to interact and obtain support from others (e.g. face-to-face support groups) difficult, almost impossible. Fortunately, today, adolescents have the feasibility to connect to the internet from literally anywhere—from school, a hospital room or at home, using a variety of electronic sources, such as tablets, cell phones, and laptops. For adolescents with CF, online communication is an important facilitator of connections to others with CF and to receipt of disease-specific support since they are not able to interact in person.

Many online studies that have examined adolescents' behaviors in social networking websites have done so in general social networking websites (e.g. Facebook, MySpace). There are not many studies that have examined adolescents' behavior in social networking website specific to a shared interest or concern among community members (e.g. having a specific illness). This is most likely due to the fact that majority of the specific- interest social networking websites are for adults, even though most internet users are teenagers. Only a few studies have examined adolescents' behaviors on social networking sites, specific to a chronic illness, and only one pilot study examined the effects of a social networking site specific to adolescents with CF (Johnson, Ravert, & Everton, 2001). None to our knowledge has examined supportive behaviors of adolescents with CF on a social networking website specifically for them, as in the current study.

Similar to face-to-face support groups, online peer support has been shown to have beneficial effects on psychological well-being and disease management for adolescents. Starbright World® is a “virtual environment” designed to provide children and adolescents with information about their illness and treatments, promote interactions among peers with the same illness, and provide entertainment and distraction. Battles and Wiener (2002) reported that the use of Starbright World® had a positive effect on the psychological well-being of children and adolescents with a chronic illness. Participants reported less loneliness, fewer withdrawn behaviors, and a sense of connectedness with others who have the same illness. Starbright World® also appeared to have a positive effect on disease management. Children and adolescents were more willing to return to the hospital for treatment after using Starbright World, indicating that the program may have had a positive effect on adherence as well.

Other researchers have reported similar results. Hazzard, Celano, and Collins (2002) found that youths with SCD who participated in Starbright World reported increased perceptions of support, whereas youths with asthma showed a positive trend in knowledge of their illness. In addition to increased knowledge, Davis, Quittner, Stack and Yang (2004) found that children and adolescents with CF evidenced better coping strategies in peer-related situations after using Starbright World®. Thus, most research shows that this digital program facilitated communication among children and adolescents with a chronic illness and had positive effects on health and psychological well-being outcomes.

In terms of disease-specific online support, a recent study, found that youth (ages 11 to 16 years) with asthma and allergies reported significantly less social isolation and

loneliness after participating in an online support group for three months. The online intervention consisted of weekly synchronous chats facilitated by older peers with asthma and/or allergies and health professionals, a community board for users to post messages to the community at any time day or night, and the option to email individual users anytime. Participants also attributed perceptions of greater confidence and a sense of normality to the support they obtained from peer mentors and peers on the website (Letourneau et al., 2012).

Positive effects were also observed for adolescents with cerebral palsy or spina bifida who attended a social network site specific to their disease. The online support website included weekly chats run by older patients with either condition or health care professionals, a message board in which messages could be written to the community, and an option to email to network members. Users found the website to be “helpful” and “fun” after participating for six months (Barnfather, Stewart, Magill-Evans, Ray, & Letourneau 2011). They also reported decreases in loneliness, and increases in social acceptance and confidence post-intervention (Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011). Note that for both of these studies, conversations among users were moderated. Thus, teens’ discussions were facilitated by someone with greater authority who could influence these interactions. This is different from the CFfone™ website, in which “chat” interactions take place without a moderator.

As mentioned previously, there is only one study that examined the effects of a disease-specific social networking website for adolescents with CF. Unlike most other studies, this website was not moderated. Johnson, Ravert, and Everton (2001) conducted a pilot study of thirteen adolescents (median age was 13 years) and found that the number

of peers in the adolescent's network and the adolescents' perceptions of peer support increased after being on the website for 10 months. In contrast, adolescents' perceptions of knowledge of CF (as reported on a survey in which participants had to rate on a likert scale, (1) strongly disagree to (4) strongly agree, the item "I know everything I need to about CF") decreased after website participation compared to their pretest scores, but their actual knowledge of CF (as reported on a quiz developed by the researchers) did not change. Although this study indicated that online social networking could be a promising intervention for increasing peer support, it had several limitations, including a small sample size (n=18), restriction of network participation to patients from only one clinic, and infrequent use of the website by participants (average log in was only four times a month). This study was also conducted in 2000, when only about 73% of teens accessed the internet, compared to 95% in 2012. A time, when only 5% of homes had broadband connections, compared to the 62% today, and teens engaged mainly in instant messaging (Lenhart & Madden 2007; Zickuhr & Smith 2012). The novelty and lack of accessibility of the internet could have had an effect on the adolescents' usage of the site which could have minimized the effectiveness of the SNS. Therefore, there is a need for current research to examine the effectiveness of SNS for adolescents with CF at the present time when the internet is frequently available and used by almost all adolescents. Despite its limitation, this study was the first pilot program to offer this innovative type of social support to adolescents with CF. The current study had a larger sample, included adolescents from several CF centers, and added a qualitative component to the analyses to further evaluate the supportive behaviors of adolescents.

Most studies providing support on online networking sites have focused on information support. One qualitative study of adolescents with cancer reported that their “electronic” friends provided functional and emotional support in three main areas: treatment-related fear, concerns about altered appearance, and school worries. In addition, online friends were preferred over regular friends (Elwell, Grogan, & Coulson, 2011). Similarly, Barnfather and colleagues (2011) found the provision of informational and emotional type of support was provided most often to adolescents with cerebral palsy or spina bifida. However, these data were reported by the moderators, rather than the participants. Similar results were found for a social networking site specific to adolescents with a chronic kidney disease, with most discussions centering on common interests (both disease-related and nondisease-related topics; Nicholas et al., 2009). Ravert, Hancock, and Ingersoll (2004) conducted a qualitative study in which they analyzed messages (n = 340) from adolescents with diabetes posted on web-based forums. They found that the provision of informational support was more common than emotional support and that “social support” was the dominant topic of discussion among users. Social support was defined by the researchers as unique support provided by users with the same disease.

Coulson (2005) also found informational support to be the most frequent type of support adolescents with irritable bowel syndrome (IBS) provided. The most common topics were symptom interpretation, illness management, and interactions with health care providers. The study with adolescents with CF (Johnson, et al., 2001) reported that users discussed non-CF vs. CF-related issues more often. Different types of peer support were not examined. In summary, informational support appears to be the most common

type of support provided on online social networking sites across chronic illnesses and that the topics of discussion are primarily related to the disease.

To date, no studies have examined the types of peer support and topics of discussion occurring on a social networking website specific to adolescents with CF. The current study examined four types of social support: companionship, emotional, informational and instrumental support. Topics were also categorized as CF- and non-CF-related. It is expected that informational support and CF-related topics will be the most common on the CFfone™ website. Note, that prior studies have indicated that instrumental support is difficult to capture in an online environment (Bambina, 2007; Elwell, Grogan, & Coulson, 2011; Mo & Coulson, 2008). Therefore, it was coded in this study but was expected to be fairly rare.

In terms of demographic differences in the usage of SNSs, Lenhart and colleagues (2011) reported that adolescents' usage of general social networks (e.g. Facebook) is consistent across sex but differs by age. It was found that older adolescents, ages 14-17, engaged more frequently on SNSs than younger adolescents, ages 12-13 years. However, the usage of online social support sites specific to a disease seems to vary across gender and age, and by disease population. A site specific to adolescents with cerebral palsy or spina bifida found girls to post more messages than boys (Barnfather et al., 2011), which was also seen in a forum specific to adolescents with diabetes (Ravert et al., 2004). However, an opposite gender effect was found for adolescents with asthma and allergies in which boys tended to engage more in chats than girls in a social network website specific to adolescents with asthma and allergies (Letourneau et al., 2012). Only one study further examined gender differences on the function of a disease-specific site

(Ravert et al., 2004). Ravert and colleagues found that males sought more informational support than females and that the topics of discussion on a SNS specific to adolescents with diabetes did not differ between male and female users.

In addition, Ravert and colleagues examined age differences, reporting that older adolescents (ages 14-16 years) posted more messages than younger adolescents (ages 11 to 13 years) and that the topics of discussion of the site did not differ between the two age groups. More research is needed to examine how SNS behaviors differ across gender and age and to determine if these differences are consistent across disease population. The current study examined gender and age differences in the frequency and function of website usage on a SNS specific to adolescents with CF. We predicted that females would be more active users and engage in the provision of emotional support more than males and that males would provide more informational support than females. Although, Ravert and colleagues (2004) found males to request more informational support which is different than support provided, the authors of the current study predicted that males would also be more likely to provide most of the informational support compared to females and compared to the other types of support. We also predicted that the topic of discussion (CF-related versus nonCF-related) would not differ between males and females.

Since there is not much research on age differences on the function of disease-specific SNS, the hypotheses for this study are based on typical developmental characteristics unique to younger and older adolescents. Developmental demands and priorities are different in the beginning versus later of the adolescent period, which is reflected in their interactions with peers. Younger adolescents tend to base their

friendships based on common interests and activities versus on intimate issues which is seen in older adolescents. Younger adolescents also tend to be reluctant to explore other social networks versus older adolescents whom have a more developed self-identity that gives them the confidence to test other social networks (Brown & Larson, 2009; Buhrmester & Prager, 1995). The developmental demands also have an effect on adolescents' perspectives on chronic illness (Quittner et al., 2011). Younger adolescents tend rely on authority (parents, healthcare providers) on the care and management of their health whereas older adolescents tend to take more of an active role in the care and management of their disease. This may be because older adolescents are more cognizant of the consequences associated with not being adherent to treatment and physician orders. Noppe and Noppe (1997) reported that the concept of death differs between younger versus older adolescents. Younger adolescents tend to feel that death is not imminent and or a possibility for them (reaffirming the invincibility fable) whereas older adolescents are aware of death being a possibility for themselves and others and integrate that knowledge into their behavior and beliefs. For this study, we predicted that older adolescents versus younger adolescents would be more active on the site and provide more emotional support and engage in more CF-related discussion. We expected that younger adolescents would provide more companionship support than older adolescents.

In summary, social support from peers with the same illness has been shown to be beneficial for psychological well-being and disease management, whether it is obtained face-to-face or online. Given that adolescents with CF are segregated and not allowed to meet with others who have the same disease, online support provision may be particularly important for this population.

Recently, a social networking website was developed specifically for adolescents and adults with CF, which is part of our NIH-funded cell phone intervention protocol, CFfone™ (NIH funded R44 SBIR Phase 2; Marciel, Saiman, Quittell, Dawkins, & Quittner, 2010). Prior to launching this website, focus groups and individual interviews were conducted with adolescents and adults with CF, parents of teens with CF, healthcare providers, and technology experts. Results indicated that there is a need for this type of intervention and may lead to improvements in knowledge of disease management, adherence, and social support. A small number of adolescents piloted the website and its features (via a computer and cell phone) and reported that they were able to navigate through the website and its features without difficulty (Marciel et al., 2010).

This intervention brings together two innovative technologies, the World Wide Web and the smart phone, to provide continuous access to a social networking website that does not require a computer. We are currently evaluating this SNS in a randomized controlled trial at six CF Centers across the U.S. In addition, others with CF have been invited to join this online community to populate the site and increase activity. The current study examined the social support exchanges that occurred on the CFfone™ SNS.

### **The Current Study**

The purpose of this study was to examine the characteristics of social support provision among adolescents with CF interacting on a social networking site. The aims of the study were as follows:

1. To evaluate consumer use of a social networking website over one academic year.

- a. To estimate the uptake of this national website among adolescents with CF over a one year period. It was hypothesized that there would be an increase uptake of the website over time.
2. To evaluate the type and frequency of support provision at four different transition points during the year.
  - a. To assess the types of support provided by participating adolescents (emotional, instrumental, companionship, informational). It was hypothesized that informational support would be provided more often than other types of support (e.g., emotional).
  - b. To identify the issues or stressors that prompted provision of support. It was hypothesized that teens would discuss illness-related issues more often than general, non-CF issues on this site.
3. To assess the most frequent stressors that elicited the provision of each type of support on the website. No directional hypothesis was made.
4. To evaluate users' responses to supportive interactions (e.g. appreciating receipt of supportive comments), in relation to level of activity on the website (posting main posts and supportive responses). It was predicted that the more users' perceived interactions as supportive, the more frequently they would "chat" on the website.
  - a. To examine how adolescents' demographic characteristics (gender and age) influenced both the frequency (enrollment and participation) and function of use of the website.

- b. Comparisons of the frequency of threads initiated, the frequency of supportive responses, the types of support provided to other users, and the most frequent issues discussed on the website were coded, and interactions between the most frequent issues discussed and support provision were compared in male and female users. It was hypothesized that females would join and utilize the website more frequently than males, and they would provide more emotional, but less informational support than males.
- c. In terms of the most frequent issues discussed (CF-related versus non CF-related), no gender difference were expected. No directional hypothesis was made for interaction effects between the type of issue and the type of support provided.
- d. Age comparisons (younger = 11-14 vs older = 15-18 years) were made on the following variables: 1) frequency of threads initiated, 2) frequency of supportive responses, 3) types of support provided, and 4) most frequent issues discussed on the website. It was hypothesized that older adolescents would join and utilize the website more frequently, provide more emotional support, and discuss issues specifically related to CF than younger adolescents. No directional hypothesis was made for potential interaction effects between type of issue discussed and type of support provision.

### Participants

The social networking website, CFfone™ (www.cffone.com), was made available to the public with funding by National Institutes of Health (NIH; R44 SBIR Phase 2 to PI Kevin Dawkins and Co-PI Alexandra L. Quittner, PhD) on Oct 2010. The website was part of a longitudinal, IRB-approved, randomized controlled trial (RCT), to examine the effects of a disease-specific SNS on knowledge of disease management, treatment adherence, perceived social support, and psychological well-being in adolescents with CF.

The website was designed for adolescents (ages 11 to 18) and adults (older than 18 years) with CF, with each age cohort using its own messaging wall. This study examined the messages posted only on the adolescent website wall during four months of the academic year (i.e., transition times) spanning September 2011 to June 2012 (n=3361). By the end of June 2012, there were 134 adolescents registered on CFfone™. To be included in this analysis, users had to post at least one message on the wall during these four months. Thus, 74 adolescent users made up the study population and were, on average, 14.53 years of age (SD= 2.06), with 71.6% females. Of this sample, 21 were recruited and consented for the CFfone™ trial.

The CFfone™ trial is a longitudinal study (initiated in April 2011 and is ongoing) composed of 101 participants (ages 11-21 years), recruited from 6 CF centers across the U.S. Participants for the CFfone™ trial were randomly assigned based on their age and FEV1% to either the intervention group (CFfone™ website) or the control group (an educational CF website) and followed for 9 months. Assent and consent was obtained

from all participants and their parents at their baseline visit. Assessment visits were conducted intermittently every 3 months during which participants completed a series of questionnaires on knowledge of disease management, adherence, perceived social support, and psychological well-being. Pharmacy refill data were obtained from individual patient's pharmacies, with parental consent, to calculate rates of adherence. Although all participants were required to have daily access to the internet, participants in the intervention arm of the trial were given a web-enabled cell phone for quick and easy access to the CFfone™ website.

### **CFfone™ website and its features**

The website was advertised on other social networking sites (e.g. CFRI, Facebook, Twitter) and professional listservs (e.g. nursing, psychology) to populate and increase activity on the website. To join the online social networking website, participants had to complete a registration process, which entailed providing their birth date, gender, contact information, and parent's contact information. Parents were then sent an email requesting permission for their child to be part of the online social networking website, CFfone™. Once parents provided permission via email, participants were able to complete the registration process and create a user name and password, which was required to access the website.

After the registration process, participants were instructed to create their online profile by providing information about themselves (e.g. hobbies, interests, biography) and posting a picture, which only members of the CFfone™ community were able to see. Participants also had the option to select other users as friends and post messages either on their own wall or on their friends' walls. They also could choose whether to have

their posted messages public or private (allowing only the target recipient to view the message; with the exception of the website monitor). In addition to the chat feature, the CFFone™ website had other features, including alerts and reminders, educational links and pages, quizzes on health and mood, and profiles of successful patients with CF. All website content was available via a “smartphone” or internet accessible devices 24 hours a day. Participants could also adjust their privacy settings and determine the exclusiveness of their profiles (i.e., access for all members of the CFFONE™ community or only their selected CFFONE™ friends; see Figure 1 for a snapshot of the CFFONE™ website).

### **Procedure**

**Monitoring safety on the website.** Given the relatively young age of the participants and lack of data on the safety of social networking sites for children with chronic illnesses, NIH mandated ongoing supervision on both the medical and psychological content of the website. The website was monitored by a graduate psychology student for incorrect medical information or concerning messages (e.g. obscene language, incorrect health information, psychological distress). Website exchanges were monitored every other day, looking back to the previous day to ensure that all website exchanges were reviewed.

We developed monitoring rules which were expanded in response to psychological crises that emerged in the online community. The following rules were used to ensure participants’ safety:

- 1) Posts with inappropriate language were flagged and removed by the Webmaster;
- 2) Posts about intense, negative emotions (angry/sad/anxious) led to closer

monitoring of the user's subsequent posts and the postings of others in response. If the user continued to post psychologically distressing comments, the Co-Investigator of the study, a licensed psychologist, was contacted immediately and informed of the situation. Intervention options were discussed and if warranted, action was taken.

3) The first level of intervention was a private email sent by Dr. Quittner to the user's email. Depending on the seriousness of the issue (e.g., sad thoughts vs. suicidal comments), Dr. Quittner also contacted the parents to discuss the adolescent's posts and to review the risk for self-injury or harm with the parent. Referrals were made when necessary. An alert was also sent to the participant's CF pulmonologist, via phone or email, or to the on-call attending physician.

4) Posts that entailed provision of incorrect information were flagged and correct information was delivered to website participants in the form of bulletins, "important facts," or a quote from the supervising physician.

4) Posts describing the possibility of in-person meetings were flagged and monitored closely to see if concrete plans developed (e.g., date, time, and location of meeting). The supervising psychologist intervened when necessary. On one occasion, the psychologist contacted two users who were planning to meet in person. Dr. Quittner had individual discussions with each teen to review the rationale for infection control and the risks of meeting in person. She also advised them to obtain a current sputum sample or result from their CF Center to determine if either one was colonized with mutiresistant bacteria. Both adolescents agreed to request current sputum cultures from their CF Center and to

communicate these results to each other prior to an in-person meeting.

5) Users had the option of deleting any posts they did not like or found offensive on their wall and could also contact the Webmaster with any concerns about a specific post. Although participants were anonymous on the website, the Webmaster had participants' and parents' contact information, which was provided during the registration process, to ensure that users and/or parents could be contacted directly in case of an emergency.

**Ethics and confidentiality.** As stated previously, the NIH required the website to be monitored as part of its ethical approval of the study. Therefore, all posts were accessible to the researchers for review and data from the website could be aggregated for analytic purposes. Furthermore, the site informed the users and parents of the public nature of the website and the fact that the posted information could “be collected and maintained by [the website owner] and by other users of the CFfone™ site.” This obviated the need to get informed consent from the public users who chose to join a website in the “public space” (Eysenbach & Till, 2001; Sudweeks & Rafaeli, 1995). Thus, this study focused on the messages posted publicly on the wall which were available to the CFfone™ community; private messages and messages deleted by the user within four hours were not considered.

One of the potential benefits of online social networking communities is the guarantee of anonymity. Users were identified on the website by the usernames they selected. In addition, their physical appearance and demographic characteristics remained private to the extent they chose. Users had control over how much information they disclosed to the CFfone™ community. As a consequence, full demographic

information on website users was not available. All other identifying information obtained at registration (email addresses, phone numbers, and names) was considered strictly confidential and stored in a separate location, using a password-protected file, accessible only by the Webmaster. In emergency situations, the Co-PI could request this information from the Webmaster to ensure participants' safety.

In addition to anonymity, other measures were taken to maintain users' confidentiality. All identifying information was altered to protect the identity of individuals. Comments made by participants were de-identified for analysis and quotes appear as they were posted on the website, with no corrections for spelling or grammar.

**Sampling of posts during transition periods.** Four months of postings during the 2011-2012 academic year were analyzed. The following months were included: September 2011, December 2011, January 2012, and June 2012. These months were selected because they represented transitions for adolescents and were marked by the need to adapt to changing conditions (e.g., beginning of a school year, holiday break, resumption of school, end of academic year). Given the need to navigate these social and academic transitions, we were interested in how teens managed their chronic illness during these periods.

Across these four months, 3352 messages from 74 adolescent users were posted and analyzed. The following posts were excluded from the content analysis: 1) posts with no accompanying text (e.g., emoticons), 2) posts that were unintelligible (e.g. acronyms, random letters and numbers), and 3) posts in a language other than English and Spanish (the two languages familiar to coders).

Messages were organized by threads, with a main post starting the conversation, followed by responses to it. A similar format appeared on the website (main post followed by corresponding responses). Users had the option to write a main post or make a comment to one that had been posted. Threads on the website were organized in chronological order and then copied and pasted into a Word document for analysis. Although the threads were left on the website wall for an unlimited amount of time, for this study, only threads and responses made within one calendar month were used in the analysis. An exception was made for threads that were initiated during the last week of the month; posts made in response to a main post were coded into the following week (i.e., first week of the following month). Adolescents often responded to main posts on different days and times of the week. Therefore, the time “window” for posts and responses was set at two weeks.

**Data analysis.** In the qualitative analysis, the aims were to describe: (1) the types of social support that were provided in response, and (2) the content of the issues posted on the wall. Each post was considered a single unit of analysis, regardless of its length. The content was coded; a single post could contain more than one topic and more than one type of social support. ATLAS.ti 6.2 was used to analyze these data.

Deductive (i.e. theory driven) thematic analysis (Boyatzis, 1998) was used to examine the type of social support provided in the Responses. This type of approach uses an already-established theoretical framework to describe and organize the data. The current study coded the provision of social support into one of four types of support: a) companionship, (b) emotional, (c) informational, and (d) instrumental. This categorization was based on Cohen’s (1985, 2004) theoretical framework of support

provision, of which Bambina (2007) developed a coding scheme for assessing these types of support online. This study adapted Bambina's coding scheme to the CFfone™ posts. Bambina's coding system identified specific online behaviors that make up three of the four types of social support (companionship, emotional, and informational) proposed by Cohen; instrumental support was not coded because of the difficulty capturing tangible behaviors on a website. However, for this study, instrumental support was included, based on definitions in the literature (Bambina, 2007; Cohen, 2004).

In total, Bambina proposed 11 subcategories within the three main types of social support. Instrumental support, created and coded by the author, was based on any reference a user made about tangible assistance to another user. An additional subcategory, prayer, was created within the emotional support category because many CFfone™ users explicitly requested and provided prayers to each other on the website. Other studies examining online social support have also included prayer as a subcategory of emotional support (Elwell et al., 2011).

Content analysis was chosen to analyze the issues discussed on the SNS. Content analysis was chosen because it is useful for organizing large amounts of written communication into categories (Bauer, 2000; Joffe & Yardly, 2004). The content analysis was conducted using an inductive approach; categories were developed as issues emerged from the data. This was an iterative process in which data was reviewed several times to compare and contrast codes for exclusivity. A final coding scheme with 68 issues was established and used for further analyses. These issues were also coded in terms of the health context: CF-specific or non-CF specific.

Interrater reliability was assessed by having a second, independent rater code 20% of all posts for each month, selected randomly. Before the second rater coded independently, the author (SR) and this rater jointly coded one month of posts (a month not included in the analyses) to establish consistency. Data was exported into the SPSS statistical software (Green, Salkind, & Akey, 2000) to conduct reliability and parametric (e.g. independent t-test) and nonparametric (Pearson Chi-square test) analyses.

### **Descriptive**

Messages posted on the website were coded as either a “main post” or “response.” Tables 2 and 3 show that of the 3352 total messages coded, 1024 messages were main posts and 1978 were responses posted by others (not including responses by the original person who initiated the thread). Eighty percent of the main posts received at least one response. In addition, 99% (1961 posts) of responses entailed the provision of at least one type of social support. Table 3 shows that the number of supportive responses fluctuated over time, with a peak level of activity in January (828 responses; an average of 2.58 responses per thread). Subsequent analyses only examined the supportive responses posted (not including the person who initiated the thread) on the website.

**Interrater reliability.** Percentage of agreement and Cohen’s Kappa statistic (Cohen, 1960) were calculated to determine level of agreement between the raters for the two coding schemes (social support and topics posted) and for the additional descriptive codes that were created by the author (appreciative posts, CF-related versus nonCF related posts). Viera and Garrett’s (2005) interpretation of Kappa was used in this study. Overall, the interrater agreement indices demonstrated good to excellent reliability for all categories coded (see Table 4).

### **Website Usage and User Demographics**

The first aim of this study was to examine the national usage of the website for four months over an academic year. As expected, usage of the website increased over time. A frequency count was conducted which showed that, over the academic year, the number of users on the website doubled from 64 to 134. However, only about half of the

total number of users utilized the chat function (posted a main post and/or a response) as a means of interacting with other users on the website. Comparisons of the demographic characteristics of users who did vs. did not “chat” on the website indicated there were no gender differences ( $\chi^2(1, N=135)=3.25, p=.07$  between the two groups, but there was an age difference. Significantly more older than younger adolescents used the chat function ( $\chi^2(1, N=135)=6.60, p<.05$ ; see Table 5). An independent t-test was also conducted to examine differences in FEV%1 (an indicator of disease severity; only obtained for CFfone™ participants) between the two groups. Results showed that FEV%1 did not significantly differ between the two groups ( $t(35.98)=.82, p=.42$ ). Demographic differences were similar for all users enrolled on the website and the subsample of users who chatted on the websites. In comparison to males and older adolescents, there were more females and younger adolescents among the total number of users enrolled on the website and the subsample of users who chatted (See Table 5).

### **Types of Social Support Provision and Discussion Topics**

A second aim was to evaluate the frequency of support provision, the types of support provided, and the CF and non CF topics that were discussed at the four transition points during the academic year. Table 6 reports the total frequency of the primary and secondary categories of support provided over the 2011/2012 academic year. The 12 subcategories of social support were collapsed into their primary categories for further analysis. Note that more than one social support category could be coded for a specific response.

A frequency analysis was conducted on the different types of social support provided over the academic year. Little support was found for the hypothesis that informational

support would be the most common type of support provided by users on the website. Instead, companionship support was provided most often (54%), followed by emotional (52%), and informational support (5%). Instrumental support was provided least often, which is consistent with prior literature (Balbina, 2007; Elwell, 2011; Mo & Coulson, 2008). In the few examples of instrumental support provision that were documented ( $n < 10$ ), the sample size was too small for further analysis, and therefore, were not included.

The pattern of support provision was also examined during the month in which the messages were posted, revealing a similar frequency pattern (companionship, emotional, and informational) for the months of December, January, and June. However, a different pattern was observed for September, during which emotional support was provided most frequently, followed by companionship and informational support (see Table 7).

The frequency with which different topics were discussed was also examined. Table 8 reports the total frequency of the 67 major topics discussed and coded for health context. Note that more than one topic could be coded in a single posting or response. Each topic was coded as either CF-related or non CF related context. Some topics were by definition CF-related, such as diagnosis and symptoms, however, most topics were more nuanced. For example, pain was discussed in both CF and non-CF related contexts on the website, although it was most frequently associated with CF. Pain is experienced quite commonly by patients with CF (Palermo & Harrison, 2006), especially in the head, abdomen, and chest. Thus, any discussions regarding pain in those areas were coded as CF-related. The following are example posts about pain that were related to CF:

*"ugh...coughing so much...really hurts my chest and stuff :( "*

*"someone please stop the pain and the annoyance that is in my head and my heart  
:/"*

*"staying home....chest hurts and stomach hurts from coughing so much!"*

The following are example posts about pain that are not related to CF:

*"i got my braces tightened today! don't worry, it only hurts for a few days!"*

*"yeah i'm fine the tip of my nose just hurt for a few minutes after he bit it  
hahah."*

See appendix for a description and example of all codes.

We hypothesized that CF-related topics would be discussed more often than non-CF topics, however, this was not supported by the results. Overall, non-CF topics were discussed more frequently both across and within each month (see Table 9). Although the CFfone™ website was designed specifically for individuals with CF, website users were more interested in chatting about topics that were not related to their disease.

Frequency analyses showed that the most frequent CF topics were: treatments (19%) and sickness (18%), whereas, school (11%) was the most frequently discussed non-CF related topic across the year. An example of a discussion of CF treatments is reported below:

**Main post:** *"kinda in a slump! anyone else ever feel like all their life is ,is wake up  
do meds eat then school and then do meds and eat again then do the same  
thing all over again the next day!!! :("*

**Response 1:** *"all the time!."*

**Response 2:** *"i think it, but never believe it"*

**Response 3:** *“i'm trying to make my life more eventful and fun, so that it doesn't feel like that evryday! :)”*

**Response 4:** *“i do often, but then i start listing off things that i'm thankful for. then i smile and feel happier :).”*

As mentioned earlier, specific transition months were selected to monitor how adolescents experienced these higher periods of stress (e.g. starting school, graduating from school). December was the only month that appeared to demonstrate a different pattern of website activity. Discussions of the upcoming holiday were very frequent and on Christmas day, there was a great deal of website activity with people exchanging holiday greetings and wishes. The following example was typical of these discussions:

**Main post:** *“merry merry merry happy christmas! :d what did y'all get?”*

**Response 1:** *“a pink bb gun,a phone,clothes,and a country dance video game for my wii.”*

**Response 2:** *“merry christmas and i got a camera, a webcam, and lots of other stuff!! :d.”*

Another aim was to evaluate how different topics elicited different types of social support. These analyses were descriptive and no directional hypotheses were generated. Companionship support was provided most often in relation to non-CF topics, such as pop culture, demographics (sharing information such as age, gender, grade in school,

etc.), and salutations (saying hello or goodbye) than with CF-related topics. Similarly, emotional support was provided in relation to postings about school, romance, and feelings.

The expression of feelings varied in valence from positive to negative. We had to increase the monitoring of the website during some of these months because users posted intense expressions of sadness or anger. Although the website users often provided support to the person in distress, a psychologist also intervened to ascertain safety, create a referral or treatment plan if necessary, and alert parents.

The opposite pattern was found for informational support. This type of support was provided primarily in response to CF-related topics, such as symptoms, treatments, and medical procedures. It was rarely provided in the context of non-CF specific topics. The thread below illustrates a typical exchange about a medical procedure:

**Main post:** *“hey guys, so next monday i'm getting a picc line in. it's the first one i've had in a long long time so to be honest, i don't remember much. can someone comment or text me and just, i don't know, update me on what it's like and everything? i'd really appreciate it. here's my # (i trust you guys) <3”*

**Response 1:** *“first off, i'm sure you'll be fine :) second, i haven't had a picc line without sedation in a while (i have issues with needles and threading the line, so they have to sedate me), but from what i remember, it was never too bad. it's not fun and it can be uncomfortable, but the nurse who did my picc lines always did the best he could to make sure i wasn't in any pain. the most i ever felt was the lidocaine and pressure when they thread it. truth be told, the anxiety was always the worst part. sorry I couldn't be more help :( good luck, though!.”*

**Response 2:** *“so basically the same as what Response 1 said- i've had so many its not even funny! (i have a port now) basically if you're sedated you go to sleep without one and wake up with one! :) it might be sore for like a day cause if you haven't had one in a while your body might not be used to it. for showers you wrap it up so it doesnt get wet. i've been awake for most of mine with some loopy medicine (it makes me see like 3 heads and i slur my words and laugh @ like everything!!) any how its really not tat long of a process it will mostly be the sedation that takes the longest. i'm sure you will do fine!! in and out and you'll be fine!! :) good luck!! xoxo.”*

Tables 10 and 11 show the relationship between the types of social support and non CF and CF-related topics. Table 12 further highlights the most frequent topics of discussion for each type of social support provided each month.

### **Perceptions of Website Supportiveness**

Another aim was to examine perceptions of support on the website and how they related to website usage. It was predicted that more expressions of appreciation would lead to increased “chat” on the website. Obtaining perceptions of support from users in an observational study can be challenging since they are not reporting directly on their perceptions of support provision. For this study, we utilized appreciative comments (e.g. “thank you”), in which users expressed thanks or appreciation for the support received, as a proxy measure of positive, perceived support.

An example of an appreciative response is appears in the following post:

“i love u all on here.thank you guys for being here for me through rough times. never belive that there isn't a cure.keep fighting!”

Table 13 shows that approximately 6% of messages posted on the website were appreciative comments. In examining the demographic characteristics of users who made these comments, females and younger adolescents posted more appreciative comments than males and older adolescents. Also, a greater proportion of appreciative comments occurred when support was provided in response to a CF-specific topic (7% of all CF-related comments) than non CF topic (5% of all non CF related comments).

A correlation analysis was conducted to examine the relationship between number of appreciative comments and chat activity (frequency of main posts and responses made on the website). Results confirmed our hypothesis. There was a positive relationship between appreciative comments and chat activity, with more positive comments associated with greater chat activity  $r(74)=.91, p<.01$ .

### **Gender and Age Differences**

Gender and age differences in support provision and discussion topics were also examined. In comparison to females and younger adolescents, males and older adolescents tended to initiate more threads than supportive responses.

**Gender differences.** In terms of the frequency of supportive responses, a significant gender difference was found. As hypothesized, an independent  $t$ -test indicated that females posted significantly more supportive responses than males,  $t(39.12)=-2.39, p<.05$ . Also, as expected, females engaged in the provision of emotional support the most followed by companionship, informational, and lastly instrumental support. The pattern of support provision was different for males, although it was not what had been hypothesized. Male users engaged in the provision of companionship the most (not informational as it was hypothesized) followed by emotional, informational, and lastly,

instrumental support. Independent T-tests were conducted to evaluate whether the frequency of each type of social support significantly differed by gender. Results showed that the frequency of companionship and informational support significantly differed between males and females; females provided significantly more companionship support ( $t(39.22) = -2.92, p < .05$ ) and informational support ( $t(44.02) = -2.85, p < .05$ ) than males.

In terms of gender differences on discussion topics, a frequency count showed that both males and females preferred to discuss non CF-related topics over CF-related topics. Independent t-tests were conducted to determine if the frequency for each type of issue discussed statistically differed between males and females. Statistically significant differences were found. Females tended to engage in more nonCF ( $t(39.22) = -2.20, p < .05$ ) and CF-related discussions ( $t(39.44) = -2.82, p < .05$ ) than males.

As can be seen in Table 9, males and females engaged in similar conversations for CF and non CF-related issues, with the exception of the topic, school. Females seemed to discuss school issues that were not related to CF, whereas, males more often discussed school issues in relation to CF.

Topics of discussion were also examined in relation to the specific type of support provided between males and females. A frequency count showed that both males and females engaged more in the provision of companionship and emotional support for topics related to non CF than CF topics. Gender differences could not be examined for the provision of informational support for CF versus non-CF related topics, due to the small number of posts made by male users ( $n=2$  for CF-related posts;  $n=4$  for nonCF-related post).

Gender differences were also evaluated in terms of interactions between frequently discussed topics and types of support provision. These interactions were exploratory; therefore, no directional hypotheses were made. As can be seen in Table 12, there were no gender differences on the topics that elicited companionship and emotional support. This was found for non CF- related topics. Gender comparisons were not possible with CF-related issues because few males posted these types of messages. However, gender differences were found for non-CF related topics, which elicited the provision of informational support. Females tended to obtain more informational support for non CF-related topics, such as using the website (CFfone™), having a therapist, and other illnesses (e.g. allergies), whereas, males obtained informational support mainly for non CF-related topics, such as the use of technology (e.g. using a cell phone or laptop).

**Age differences.** Age differences were also evaluated for frequency of total supportive responses and amount type of support provision. It was hypothesized that older adolescents would provide more supportive responses than younger adolescents. Although the frequency of total supportive responses posted on the website differed between the two age groups, younger teens posted more responses than older teens, however, it was not statistically significant ( $t(52)=0.9, p=0.37$ ). The pattern of support provision, however, differed between younger and older adolescents. As hypothesized, younger adolescents provided companionship support most often followed by emotional and informational support, whereas older adolescents provided more emotional support, followed by companionship and informational support. Independent t-tests were then conducted to examine whether the frequency of each type of social support significantly differed between the two age groups; no differences were found.

In terms of age differences for the topics discussed on the website, both younger and older adolescents preferred to discuss non-CF versus CF-related topics. Independent t-tests showed that the frequency of non-CF and CF-related topics did not significantly differ between the two age groups. As can be seen in Table 9, many similarities were observed for the types of CF issues discussed (e.g. treatment and sickness) between younger and older users. However, differences were seen in the most frequent topics discussed that were *not* related to CF. Younger adolescents discussed about the website (website users and features) and extracurricular activities, whereas the older adolescents discussed alternative methods of communication with website users outside of the CFfone™ website (via Skype, text messaging) and romantic relationships. Both age groups, however, frequently discussed school-related issues that were not related to their disease. The following thread is an example of a school topic frequently discussed that is not CF-related.

**Main post:** *“anyone else horrible at math? (:”*

**Response 1:** *“me!! taking geometry. how about you?.”*

**Response 2:** *“im taking college prep alegebra ii :p.”*

**Response 3:** *“sounds fun :p i think i'd rather do algebra than geometry any day.”*

Age differences were also evaluated for the interactions between the most frequently discussed issues and type of support provision. Once again, these interactions were exploratory and no directional predictions were made. As can be seen in Table 12, there were no age differences in the type of topics that elicited companionship and emotional support. The provision of both, companionship and emotional support tended to occur

more with nonCF-related topics than CF-related topics. In addition, no differences were found for the most frequent type of topic that elicited informational support.

Informational supported tended to occur the most for CF-related topics for both younger and older adolescent users.

In examining the specific topics that elicited the different types of support, younger and older adolescents provided companionship and emotional support for similar topics of discussion. Differences were found for non-CF related topics that elicited informational support. Younger adolescents obtained informational support primarily in the context of non CF-related topics, such as use of the CFfone™ website and friends, whereas, for older adolescents, informational support was obtained in relation to non CF-related issues, such as having a therapist and the use of technology.

## Chapter 4: Discussion

This study examined the nature and function of peer support on a social networking site designed specifically for adolescents with CF. CF is currently the only chronic illness which requires complete segregation of patients, which has severely limited peer-to-peer support. A major aim was to examine the uptake of this website and determine which types of support were provided most often and which topics elicited various types of support. Content analyses were performed to examine users' activity on the website across an academic year. In addition, specific months during this period were targeted because they marked important transition points in the adolescents' school year (e.g., starting a new year, holiday break). To our knowledge, this is the first randomized controlled trial testing the efficacy of a social networking site for adolescents with a serious, chronic illness.

Results indicated that only about half of the total users enrolled on the website actually participated in the online discussions. Although the network size of adolescents who participated in the discussions is larger in the present study than the network sizes reported in other studies, that have examined social support in websites specific to adolescents with a chronic illness, it is important to examine reasons why some of the adolescent users did not participate in the exchanges of online peer support online.

One possible reason could be that the adolescents did not have time to be on a SNS due to their hectic schedule which consist of attending school and extracurricular activities, doing homework, and doing their treatment for CF. Studies have found that being a "lurker", which is defined as someone watching the interactions and activities on the website and obtaining only information relevant to the self but not posting or

responding to messages, takes significantly less time and energy than being a “poster” on a SNS (Nonnecke & Preece ,2003; Mo & Coulson 2010). Nonnecke and Preece (2000) estimated that on average 46% of the users of a health-related online support group are “lurkers”, which would be approximately what was observed in the present study if all the users who did not participate on the website were lurkers. Unfortunately, we had no way of determining whether that the adolescents who did not post on the discussion wall were “lurkers” or users who did not log onto the website at all.

Another possible explanation as to why users did not participate on the disease-specific SNS could be that their disease was not as severe as the other users’ (those that posted messages) disease, and that their disease did not take much of their focus and attention (e.g. fewer hours of treatment, fewer hospitalizations), as it may have for the other users. Therefore, they probably did not want to be reminded or think about how severe their disease can get if they were not currently experiencing any challenges or difficulties with their disease. This was observed in a recent study in which adolescents who were minimally affected from cerebral palsy or spina bifida reported not needing a disease-specific intervention such as an online support group (Barnfather et al, 2012).

Another possibility for adolescents not engaging in chat communications could also be because they already have an established, supportive network which they have no interest of changing. Cohen, Underwood, and Gottlieb (2000) advised that support interventions that entail introducing new ties are most effective when existing ties are weak and not supportive. This is consistent with what studies have found that majority of adolescents prefer to chat online with existing friends than with strangers (Peter, Valkenburg, and Schouten, 2006; Subrahmanyam et al., 2008). Reich and colleagues

(2012) recently reported that about 77% of adolescents' online social networks are composed of friends who they know in person. Researchers probably need to investigate ways to help teens feel comfortable interacting with a group strangers. Maybe having a moderator to facilitate the process of the users getting to know each other (e.g. providing an ice breaker) might entice users to further get to know their peers.

Lastly, there is the possibility that the users who did not engage in the online chats could have not had any other mutual interests, than having CF, with the other members on the website. Nicholas and colleagues (2009) found that adolescents with a chronic kidney disease tended to participate more on a disease-specific website when there were more interests in common (other than the disease they had; e.g. close in age, living in the same city) among the users than when there were no interests in common. All these possible reasons for why some adolescents choose to join a SNS but not to participate in discussions should be taken into account when considering to implement an online support intervention.

Another aim of this study was to identify the most frequent type of social support and topic of discussion adolescents with CF engaged in on a SNS specific to CF. The results demonstrated that the main function of the SNS was to provide companionship support followed by emotional and informational support. There were very few instances of instrumental support that were coded for this study which is similar to what has been reported by other studies (Coulson, 2005). The few instances coded were not even the actual behaviors in action; instead they were references to the tangible type of behavior (e.g. "thank you for the pizza"), therefore, as other studies have done, it is best to omit instrumental support when evaluating online social support (Elwell et al., 2011; Bambina,

2007). The finding of companionship support being the primary type of support for the SNS specific for adolescents with CF does not confirm what previous studies have found with other disease-specific SNS; but then again most of those studies did not examine or code specifically for companionship support. Although, there is one study that examined network support in a SNS for adolescents with IBS, which is similar to companionship support, network support was not the primary type of support for the SNS for adolescents with IBS. Instead, informational support was found to be the primary function of support, followed by emotional support (Coulson, 2005). This is similar to what other studies have reported that informational support was the most frequent type of support provided on online sites (Barnfather et al., 2011; Coulson, 2005; Ravert, Hancock, & Ingersoll, 2004). A possible explanation for the different findings could be that the disease populations differ in their needs from peers. This would not be surprising due to the fact that different illnesses have different symptoms, different disease courses, and different treatment regimens which affect individuals' lives differently (Quittner et al., 2011). It could be that adolescents with CF tend to need more companionship from their online, same-illness peers due to the extreme restriction that prohibits them from obtaining companionship physically, which adolescents with other chronic illnesses are able to do.

The type of issues most frequently discussed on the SNS were those not related to CF, or also known as the typical issues that all adolescents (even those without a chronic illness) experience, such as, extracurricular activities, the actual SNS, and school. Johnson and colleagues (2001) also found in their sample of adolescents with CF that they preferred to discuss about issues not related to CF with their peers on a SNS specific

to adolescents with CF. However, this was not found in other studies of disease-specific SNS for other illnesses (other than CF); the topic of discussion among the users for these studies were mainly about the disease they all had (Elwell, Grogan & Coulson, 2011; Ravert, Hancock, & Ingersoll, 2004). Again this can be due to the different needs associated with different chronic illnesses. Adolescents with CF do not have social gatherings (e.g. dances, camps, support groups) in which they are able to share typical, ordinary adolescent experiences, therefore it seems like online social networks is their only alternative to connect with other teens with CF and to share those typical adolescent issues. This discrepancy between the CF population and the other disease populations, emphasizes how stressors differ across chronic illness populations, reinforcing the need for SNS to be disease specific.

The topics that elicited different types of support were also examined in this study. It was found that adolescents with CF preferred to obtain companionship and emotional support from peers on nonCF-related issues and informational support for CF-related issues. This makes sense considering the fact that companionship and emotional support for CF-related issues can be obtained from other sources (e.g. parents, healthy peers, health providers) besides peers with the same illness and that companionship and emotional support for issues that are related to typical adolescent development (e.g. nonCF-related) are best provided by same aged peers, including peers with the same illness (e.g. website users). It is not surprising to find that users prefer to obtain informational support from peers with the same illness for CF-related issues since the peers (besides healthcare providers) would have the most information on their illness.

The constant exchanges of social support observed on the website during the academic year is an indication that stress is persistent in the lives of adolescents with CF. However, the levels of stress seemed to vary, requiring different types of social support and occurring across different contexts. This continual activity on the website provides evidence to the main effect model of social support, which suggests that social support has a positive effect on all levels of stress. If the provision of support had not been beneficial in helping adolescents cope with different levels of stress or if the users had only needed support during times when stress was at its highest level (e.g. having surgery, being hospitalized), as the buffering model suggests, then the continual activity which was observed would not have been present. If the buffering model of social support, which suggests that support is only beneficial during high levels of stress, had been true then the teens would have only sought support during stressful situations, such as issues related to their CF, and not during situations that were not so stressful, such as being bored and starting a romantic relationship as it was seen on the website. Some users even commented on how helpful and appreciative they were of the support they had received from other users.

This takes us to the third aim of this study which examined the relationship between the number of appreciative postings and “chat” activity. Results revealed that those who frequently commented in appreciating the support obtained from the community participated more on the website than those who did not comment or commented a few occasions about appreciating the support. No other study, to our knowledge, has qualitatively captured a form of evaluation of the social support obtained on a SNS.

Although the researchers are aware that the data collected may not be representative of all

the adolescents who were appreciative of the support obtained (considering the fact that there may be some adolescents who may have benefitted from the support but may not have engaged in the etiquette of saying “thank you” to peers). Amidst the small sample size of appreciative posts, a strong relationship was detected which shows the robustness of the relationship between perceiving the support to be beneficial and the continuous involvement in online communication. This finding also provides insight to the supportiveness of the website and suggests that SNS might be an alternative method in providing positive peer support for patients with CF and possibly for patients with other chronic illnesses.

### **Gender and Age Differences**

The fourth aim of this study was to evaluate the demographic effects of gender and age on the frequency and function of usage on the SNS (the provision of social support and topics discussed). Results indicated that female users with CF were the main consumers of the SNS and participated more (in posting main posts and responses) than the male users. Similar results were found with adolescents with cerebral palsy and spina bifida and youths with diabetes (Barnfather et al., 2011; Ravert et al., 2004). A possible reason for such gender effect can be due to the fact that males and females use the internet for different purposes. Research has found females to use the internet more for interpersonal communication purposes and males for gaming purposes (Subrahmanyam et al., 2001). Furthermore, it has been found that female adolescents engage more in online self-disclose than their male counterparts (Valkenburg, Sumter, and Peter, 2011). Another explanation for the gender differences in SNS consumption and participation could be because females are more uncomfortable than males in social situations;

therefore, they turn to the internet, specifically text messaging and SNS, more than face-to-face interactions for communication (Davis, 2012; Pierce, 2009).

As for the types of support males and females engaged in, it was found that both, males and females displayed a similar frequency order in the provision of peer support; providing mostly companionship support followed by emotional support and informational support. This finding contradicts to what face-to-face support groups found; reporting that females requested and provided more emotional support. It also contradicts what Ravert and colleagues (2004) found with male users on a SNS for adolescents with diabetes who sought primarily informational support. A possible reason for this discrepancy could be that emotional support may require the presence of other components, such as visual and auditory cues, which are present in face-to-face interactions but not in online interactions. Also, the request of support, like males seeking for informational support as reported by Ravert et al (2004), may differ from the provision of support which is the type of support that the current study examined. The request of support has to do with the need that requires attention, whereas the provision of support is about the attention that is provided to the need. It could be that males with CF have the need to obtain information from others and but that they tend to provide more companionship support when others request that type of support. Another possible explanation for the discrepancy could be that the needs associated with males and females with CF differ from those associated with males and females with other chronic illnesses. More research is needed with the CF population and with other disease populations to confirm that gender differences differ across disease populations.

This study also examined gender differences in the amount each type of support was provided. The provision of companionship and informational support differed by gender, with females engaging more in both types of support. No differences were found for emotional support. An explanation for such finding could be that emotional support is obtained in more stressful, serious situations in which both males and females find the need to respond and provide support, whereas the other types of support occur in situations where stress is not so high, therefore, the females who use the internet for interpersonal communication, then to provide companionship and informational support the most. These different responses to the different levels of stress elicited from situations provide some support to the buffering effect model of support. Cohen and Wills (1985) did suggest that there may be overlaps between the two models and that more research need to be done to evaluate the different functions of social support across different contexts that elicit different levels of support and across different populations. Based on the results of this study it seems that the buffering effect model may be applied to specific types of support, such as emotional support. However, this can only be confirmed if the intensity of stress to a situation in which support is provided had been measured which could not be attained with the methodology employed in this study. Future studies may consider further evaluating the application of the two different models of support to different levels of stress within the peer context.

Gender differences were also examined for the most frequent type of topics (CF versus nonCF related) discussed and the interaction between the type of topics discussed and the type of support provided. Both males and females discussed more about nonCF-related than CF-related topics on the website. This may be because the adolescents

already have an understanding of what everyone is going thru with the management of their disease that there is no reason to complain about it with peers who are experiencing either similar or greater difficulties. However, when comparing the most frequent CF- and nonCF-related topics discussed by males and females, this study found that there was difference in the way males and females discussed about school issues. Females tended to discuss about school stressors that was not related to CF, whereas males mainly discussed about school stressors that were related to their CF. This difference could be due to how males and females differ in their perception and attitudes towards school (Ding & Hall 2007). This finding insinuates that that there are other stressors not related to CF that make females' school experience more stressful, whereas for males, factors related to their CF tend to make their school experience more stressful.

Further examination found topics not related to CF to be predominant for companionship and emotional support provision for both males and females. Comparisons were not possible for informational support due to the small number of posts by males, however, in examining the posts made by females, informational support seemed to be elicited with CF-related issues more frequently than nonCF-related issues. This finding provides support that adolescents with CF, regardless of gender, prefer to share and obtain support (specifically companionship and emotional support) from peers with the same illness on stressors related to typical adolescent difficulties (nonCF-related) than to their illness (CF-related). Only with informational support is the topic of discussion related to their illness.

Age was another factor examined in this study. The results showed that age differed in the consumption and participation of the SNS, with majority of the enrolled users

being younger adolescents. Although the amount of chat activity did not differ between the two age groups, the type of participation (making a main post or providing a response) did differ between the two age groups. Older adolescents initiated most of the dialogues (threads) by posting more main posts on the website than the younger adolescents. However, younger adolescents tended to provide more supportive responses than the older adolescents did. A possible explanation for this finding could be that the younger adolescents were eager to be part of a community everyone is joining, however are a little cautious (which may be due to the lack of confidence) to initiate conversations on the website. This apprehensive behavior may be representative of the typical developmental characteristics unique to each age group. Younger adolescents who are still in the process of defining their self-identity and refrain from being intimate with someone may lack confidence when placed in a situation with people they do not know. Older adolescents on the other hand have established their self-identity and are more intimate in their relationships, therefore, they are confident in exploring other networks and taking an initiative forming relationships (Brown & Larson, 2009; Buhrmester & Prager, 1995).

A difference in the types of support each adolescent group engaged in was observed in this study. Younger adolescents primarily engaged in companionship support followed by emotional and informational support; whereas, older adolescents primarily engaged in emotional support followed by companionship and informational support. Once again the difference in the provision of support can be attributed to different levels of mastery of developmental tasks that occur across the adolescent period. The formation of friendships has been found to differ by developmental group. Younger adolescents tend

to socialize with their core peers and tend to establish friendships based on common interests and activities which would be a context for companionship support. Older adolescents, on the other hand, have a secured sense of identity which allows them to explore other peer networks, and base their relationships with peers on intimate exchanges which would require more emotional type of support (Berk, 2009).

Results showed that both adolescent groups frequently discussed about the same type of issues, which were issues not related to CF. Younger adolescents discussed mainly of the SNS, CFfone, which they all had in common (being members of the same social network), and the extracurricular activities they were involved in, whereas, the older adolescents shared more intimate information (e.g. demographics) and discussed about other methods of communication (e.g. text messaging, video chat) other than the website. These findings confirm the dynamic process of the adolescent period; providing insight on how the limitations and challenges associated with this period are also present in online interactions.

This study also examined age differences in the type of topics that elicited the different types of social support. No differences were found. Both younger and older adolescents provided companionship and emotional support primarily for nonCF-related topics and informational support for CF-related topics. A possible explanation for such finding is similar to what has been suggested earlier. This finding provides support that adolescents with CF, regardless of age, prefer to share and obtain support (specifically companionship and emotional support) from peers with the same illness on stressors related to typical adolescent difficulties (nonCF-related) than to their illness (CF-related). Only with informational support is the topic of discussion related to their illness which

makes sense since peers with the same illness (aside from healthcare providers) would be the only source to have disease-specific information.

### **Limitations and Future Directions**

There are a number of potential limitations to the present study that should be taken into considerations. One being, that the sample used for this study is a self-selected sample. We cannot assume that the characteristics of the provision of social behavior are applicable to all patients with CF. It could be that CF patients that chose to not enroll and chat on the SNS, CFfone, have a different pattern of social support behavior. Therefore, the messages analyzed for this study are representative for adolescents (primarily females) with CF from this one SNS. Similarly, the time period of when the messages were analyzed limits the generalizability of results to those specific months, September 2011, December 2011, January 2012, and June 2012. The consumption and social support exchanges that occur at other times or on other SNS specific to CF are not known and cannot be assumed based on the findings from the present study.

Another potential limitation may be the wide range of ages (11 to 18 years) of the users on the SNS. As it has been discussed in this paper, there are substantial developmental differences and priorities across the adolescent age span. Having adolescents grouped by a smaller age range may increase participation and trigger other types of discussions and provision of support as was suggested by Nicholas and colleagues (2009).

Despite these limitations, the present study has made significant contribution to the literature providing unique insight into how adolescents with CF provide support to each other across various topics of discussions, mainly topics not related to their CF. The

extensive amount of information on peer support and topics of discussion obtained for this study would not have been possible with other methods of data collection, which have been associated with biases and confounds (e.g. social desirability, not understanding the question). Most importantly the data for this study was collected in the participants' naturalistic environment, without the presence and interference of a researcher or moderator, making the data rich and untainted by biases and confounds associated with other data collection methodology.

There are many possible avenues for future research in the field of SNS specific for adolescents with CF as well as for adolescents with other types of chronic illnesses. As was suggested earlier, there are many factors (e.g. intensity of stress, perception of support) that are best captured in other methodological approach. Future research may want to consider taking a multimethod approach, combining qualitative and quantitative data so that other factors influencing online behaviors can be accounted for. Future research may also want to consider incorporating reports from other sources of support, like teachers and parents, that way the unique support that is provided from peers with the same illness can be better understood. Once there is an understanding as to what type of support adolescents with CF seek from their peers and the topic of discussion that they prefer to discuss with their peers, future research may then want to consider developing an online support intervention in which a mediator facilitates and stimulates the type of support and stressors adolescents most benefit by sharing with peers with the same illness.

Researchers should also be aware of the challenges associated with monitoring and managing a SNS specific to adolescents with CF. In general, adolescents tend to be

moody and exaggerate on obstacles they are confronted with (Berk, 2011). However, the challenges are further magnified when adolescents have a chronic illness because they are at a higher risk of developing depressive symptoms compared to their healthy peers (Barnes et al., 2010; Quittner et al., 2008). Quittner et al (2008) specifically found that 28-30% of youths with CF reported elevated symptoms of depression. Therefore, researchers should have the expectation and be cautious of negative and depressive emotions that are disclosed on a SNS, which may escalate to a more serious situation (e.g. suicidal attempt) or cause emotional distress on other users. Access to parents' contact information should readily be available in situations of concern, since the users are under age and parents are legally responsible of their wellbeing. A more specific concern to the CF population is the desire to physically meet with others with the same illness. Fortunately, for CFfone, this situation only occurred once, thus far in the 2 years that the website has been active. However, the desire to physically meet should be monitored, since physical contact can be detrimental to the health of a patient with CF. Another issue that tends to be more prevalent in individuals with a chronic illness than healthy individuals is death. The monitoring of the website should be heightened after the death of a user to identify any user or users having difficulty with the loss of the user and who may benefit from psychological/counseling services that can help with the bereavement/grieving process. CFfone, only experienced the death of one user thus far, in the two years that it has been active. However, the user was not an active user on the site, therefore, the death of the user did not have an effect on the website activity. For these reasons and for many other concerns not addressed (e.g. suicidal ideation and other psychological disorders), the services of licensed psychologist are necessary with the

monitoring of a SNS for adolescents with a chronic illness. The services of a physician are also necessary to address the medical needs and concerns posted on the website.

### **Conclusion**

Despite the challenges associated with the management of a SNS, this study highlights the importance of a SNS for adolescents with CF suggesting that it is beneficial and valued by the adolescents. SNS allows adolescents with CF to obtain the peer support they need to cope with the stressors associated with being a teenager and having CF. Even though, individual characteristics, age and gender, may differ in the consumption and function of the disease-specific SNS, the continual use of the SNS and the engagement in obtaining and providing support is present in all users. Overall, disease-specific SNS seem to be a promising and fast- evolving alternative, that more and more adolescents are being part of, to obtain primarily companionship support and to discuss topics that affect all adolescents; however from a perspective of a peer with similar difficulties and challenges associated with having a chronic illness.

Table 1

*Demographic Characteristics for  
CFfone Trial Participants' and All  
Website Users*

Demographic variable	CFfone trial users	Total website users
N	21	74
Age (mean)	14.12	14.53
FEV% (mean)	77.76	-
Females (%)	71.4	71.6
Males (%)	28.6	28.4
Younger (%)	61.9	54.1
Older (%)	38.1	45.9

Table 2

*Main Post Characteristics*

	Sept	Dec	Jan	Jun	Total	% of total main post
N users	32	26	30	39	71	95.9 <sup>a</sup>
# Main posts	231	274	337	182	1024	100.0
CF context	49	84	81	35	249	24.3
NonCF context	186	201	258	148	793	77.4
Females	210	252	324	127	913	89.2
Males	21	22	13	55	111	10.8
Younger	85	121	195	67	468	45.7
Older	146	153	142	115	556	54.3
# Supportive threads	172	203	313	133	821	80.2

<sup>a</sup> percentage of total chat users (N=74)

Table 3

*Others' Response Posts Characteristics*

	Sept	Dec	Jan	Jun	Total	% of total responses
N users	23	23	27	26	54	73.0 <sup>a</sup>
# others' responses	436	432	828	282	1978	100.0
Average number responses per thread	2.49	2.07	2.58	2.14	2.36	-
# supportive responses	428	429	824	280	1961	99.1
CF context	133	136	271	69	609	31.1 <sup>b</sup>
NonCF context	298	299	554	212	1363	69.5 <sup>b</sup>
Females	414	421	810	258	1903	97.0 <sup>b</sup>
Males	14	8	14	22	58	3.0 <sup>b</sup>
Younger Teens	289	282	628	181	1380	70.4 <sup>b</sup>
Older Teens	139	147	196	99	581	29.6 <sup>b</sup>

<sup>a</sup> percentage of total chat users (N=74); <sup>b</sup> percentage of total supportive responses

Table 4

*Interrater Reliability for Coding Schemes*

Coding scheme	Cohen's Kappa	95% Confidence Interval	Percent Agreement (%)
Social Support	0.62	0.587 0.653	82.5
Topic of discussion	0.53	0.503 0.557	98.4
CF vs NonCF context	0.82	0.793 0.847	91.0
Appreciative responses	0.75	0.627 0.873	98.1

Table 5

*User Characteristics*

	Sept	Dec	Jan	Jun	Total	% of total
All enrolled users	65	80	87	135	135	100.0
Females	47	55	60	87	87	64.4
Males	17	24	26	47	47	34.8
Younger	39	51	55	86	86	63.7
Older	26	29	32	49	49	36.3
Non-chat users	32	53	56	93	61	45.2
Females	22	32	35	58	34	25.2
Males	9	20	20	36	26	19.3
Younger	22	38	40	66	46	34.1
Older	10	15	16	27	15	11.1
Chat users	33	27	32	42	74	54.8
Females	25	23	26	31	53	39.3
Males	8	4	6	11	21	15.6
Younger	17	13	16	20	40	29.6
Older	16	14	16	22	34	25.2

Table 6

*Number and Percentage of Supportive Responses in each Social Support Categories Provided over the Academic Year*

Social support categories	n of postings	% of total supportive postings
Companionship		
chatting	757	38.6
groupness	66	3.4
humor/sarcasm	15	0.8
Emotional		
sympathy	113	5.8
caring	136	6.9
affirmation	216	11.0
encouragement	137	7.0
praying	48	2.5
understanding	74	3.8
Informational		
advice	17	0.9
referral	0	0.0
teaching	10	0.5
Instrumental		
	7	0.4

Table 7

*Number of Supportive Responses Provided by Demographic Characteristics*

	Sept	Dec	Jan	Jun	Total	% of total supportive responses
Companionship	154	226	488	149	1017	51.9
Females	149	218	477	134	978	49.9
Males	5	4	11	15	35	1.8
Younger	113	162	368	96	739	37.7
Older	41	64	120	53	278	14.2
Emotional	274	220	374	137	1005	51.2
Females	266	218	372	130	986	50.3
Males	8	2	2	7	19	1.0
Younger	177	140	292	87	696	35.5
Older	97	80	82	50	309	15.8
Informational	27	24	28	16	95	4.8
Females	24	23	27	15	89	4.5
Males	3	1	1	1	6	0.3
Younger	14	8	23	12	57	2.9
Older	13	16	5	4	38	1.9
Instrumental	5	2	1	1	9	0.5
Female	5	2	1	1	9	0.5
Male	0	0	0	0	0	0.0
Younger	4	1	1	1	7	0.4
Older	1	1	0	0	2	0.1

Table 8

*Number and Percentage of CF and NonCF-related Topic Categories*

Topics	# of CF-related postings	% of total CF-related topics <sup>a</sup>	% of total postings <sup>b</sup>	# of nonCF-related postings	% of total nonCF-related topics <sup>a</sup>	% of total postings <sup>b</sup>
award/recognition	0	0.0	0.0	3	0.2	0.2
birthday	0	0.0	0.0	25	1.8	1.3
busy-ness	1	0.2	0.1	0	0.0	0.0
career/work	2	0.3	0.1	23	1.7	1.2
CF diagnosis	63	10.3	3.2	0	0.0	0.0
CF symptoms	77	12.6	3.9	0	0.0	0.0
CFfone™ website	13	2.1	0.7	126	9.2	6.4
Clinic	47	7.7	2.4	1	0.1	0.1
College	0	0.0	0.0	5	0.4	0.3
cure	24	3.9	1.2	1	0.1	0.1
day of the week	2	0.3	0.1	21	1.5	1.1
death	2	0.3	0.1	25	1.8	1.3
demographics	7	1.1	0.4	117	8.6	6.0
disease awareness	13	2.1	0.7	4	0.3	0.2
dislikes	13	2.1	0.7	35	2.6	1.8
eating	18	3.0	0.9	39	2.9	2.0
emotional state	11	1.8	0.6	69	5.1	3.5
exercise	7	1.1	0.4	13	1.0	0.7
extracurricular activities	8	1.3	0.4	120	8.8	6.1
facts and quizzes	5	0.8	0.3	9	0.7	0.5

family	20	3.3	1.0	76	5.6	3.9
finance/money	0	0.0	0.0	0	0.0	0.0
friends	14	2.3	0.7	56	4.1	2.9
gift/new object	1	0.2	0.1	19	1.4	1.0
health status	11	1.8	0.6	3	0.2	0.2
hobby/talent/ability	3	0.5	0.2	20	1.5	1.0
holiday	4	0.7	0.2	67	4.9	3.4
hospitalization	56	9.2	2.9	0	0.0	0.0
independence	1	0.2	0.1	0	0.0	0.0
life	5	0.8	0.3	24	1.8	1.2
lung transplant	13	2.1	0.7	0	0.0	0.0
medical procedure	45	7.4	2.3	0	0.0	0.0
medical test/exam	5	0.8	0.3	0	0.0	0.0
missing an event/activity	4	0.7	0.2	1	0.1	0.1
mistake/doing something wrong	0	0.0	0.0	7	0.5	0.4
other group/organization awareness	0	0.0	0.0	0	0.0	0.0
other illnesses	13	2.1	0.7	15	1.1	0.8
outside communication	30	4.9	1.5	96	7.0	4.9
pain	26	4.3	1.3	5	0.4	0.3
pet/animal	3	0.5	0.2	17	1.2	0.9
physical appearance	5	0.8	0.3	24	1.8	1.2
pop culture	14	2.3	0.7	121	8.9	6.2
psychological diagnosis	0	0.0	0.0	0	0.0	0.0
punishment	0	0.0	0.0	4	0.3	0.2

putting self-down/ insults to self	1	0.2	0.1	6	0.4	0.3
quote	1	0.2	0.1	40	2.9	2.0
religion	18	3.0	0.9	43	3.2	2.2
research participant	0	0.0	0.0	0	0.0	0.0
romance	7	1.1	0.4	111	8.1	5.7
salutation	4	0.7	0.2	105	7.7	5.4
sarcasm	1	0.2	0.1	1	0.1	0.1
school	64	10.5	3.3	157	11.5	8.0
sick	110	18.1	5.6	35	2.6	1.8
sleep	4	0.7	0.2	9	0.7	0.5
social event	0	0.0	0.0	20	1.5	1.0
summer break	3	0.5	0.2	5	0.4	0.3
technology	2	0.3	0.1	16	1.2	0.8
thankfulness	7	1.1	0.4	1	0.1	0.1
therapist	0	0.0	0.0	6	0.4	0.3
trauma	0	0.0	0.0	21	1.5	1.1
travel/new place	2	0.3	0.1	20	1.5	1.0
treatment	112	18.4	5.7	8	0.6	0.4
weather	2	0.3	0.1	5	0.4	0.3
weight general	7	1.1	0.4	2	0.1	0.1
well being	17	2.8	0.9	51	3.7	2.6
winter break	0	0.0	0.0	4	0.3	0.2
wish	6	1.0	0.3	3	0.2	0.2

<sup>a</sup> percentage based on total supportive responses per context; <sup>b</sup> percentage of total supportive responses

Table 9

*Top 3 Most Frequent CF and NonCF- related Topics of Discussion by Demographic Characteristics*

	Sept	Dec	Jan	Jun	Total
CF context	133	136	271	69	609
1	Treatment	Sick	Treatment	Sick	Treatment
2	School	Hospitalization	CF diagnosis	Hospitalization	Sick
3	Medical procedure	CF Symptoms	Sick	CF Symptoms	CF Symptoms
NonCF context	298	299	554	212	1363
1	Extracurricular activities	Holiday	Cffone™ website	Cffone™ website	School
2	School	Outside communication	School	Pop culture	Cffone™ website
3	Salutation	Cffone™ website	Pop culture	Romance	Pop culture
CF context Females	130	133	266	67	596
1	Treatment	Sick	Treatment	Sick	Treatment
2	School	Hospitalization	CF diagnosis	Hospitalization	Sick
3	Medical procedure	CF symptoms	Sick	CF symptoms	CF symptoms
NonCF context Females	287	295	546	192	1320
1	Extracurricular activities	Holiday	Cffone™ website	Cffone™ website	School
2	School	School	School	Romance	Cffone™ website
3	Salutation	Outside communication	Pop culture	Pop culture	Pop culture
CF context Males	3	3	5	2	13
1	Treatment	-	Treatment	-	Treatment
2	-	-	School	-	Sick
3	-	-	CF diagnosis	-	School
NonCF context Males	11	3	8	20	43
1	Extracurricular activities	Gift/New object	Cffone™ website	Pop culture	Cffone™ website
2	Technology	-	Life	Salutation	Pop culture
3	Well being	-		Cffone™ website/ Demographics	Extracurricular activities
CF context Younger	88	73	200	43	404
1	Treatment	Sick	Treatment	Hospital	Sick

2	School	Hospital	Sick	Sick	Treatment
3	Medical procedure	Outside communication	Clinic	CF symptoms	CF symptoms
NonCF context Younger	202	211	430	138	981
1	Extracurricular activities	Holiday	Cffone™ website	Cffone™ website	School
2	School	School	School	Pop culture	Cffone™ website
3	Salutation	Family	Pop culture	Salutation/ Demographics	Extracurricular activities
CF context Older	45	63	71	26	205
1	Treatment	Sick	CF diagnosis	Sick	Treatment
2	School	Hospitalization	Treatment	CF symptoms	CF diagnosis
3	Medical procedure/CF symptoms/Pain	CF symptoms	School	Romance	Sick
NonCF context Older	96	88	124	74	382
1	Extracurricular activities	Holiday	Demographics	Romance	Demographics
2	School	Outside communication	Cffone™ website	Pop culture	School
3	Romance	Demographics	Romance	Outside communication/ Cffone™ website	Outside communication /Romance

Note. (-) there is no other topic category with more than 1 observation.

Table 10

*Percentage of each Type of Social Support Provided for each CF-related Topic*

CF-related Topics	n of companion support posts	% of total companion support	n of emotional support posts	% of total emotional support	no of inform support posts	% of total inform support
award/recognition	0	0.0	0	0.0	0	0.0
birthday	0	0.0	0	0.0	0	0.0
busy-ness	0	0.0	1	0.1	0	0.0
career/work	1	0.1	2	0.2	0	0.0
CF diagnosis	38	3.7	32	3.2	1	1.1
CF symptoms	7	0.7	65	6.5	17	17.9
CFfone website	7	0.7	8	0.8	0	0.0
Clinic	12	1.2	38	3.8	0	0.0
College	0	0.0	0	0.0	0	0.0
cure	8	0.8	20	2.0	3	3.2
day of the week	2	0.2	4	0.4	0	0.0
death	0	0.0	3	0.3	0	0.0
demographics	7	0.7	2	0.2	0	0.0
disease awareness	4	0.4	10	1.0	3	3.2
dislikes	1	0.1	13	1.3	2	2.1
eating	6	0.6	18	1.8	1	1.1
emotional state	2	0.2	11	1.1	0	0.0
exercise	3	0.3	5	0.5	0	0.0
extracurricular activities	1	0.1	8	0.8	1	1.1
facts and quizzes	4	0.4	0	0.0	0	0.0
family	10	1.0	8	0.8	3	3.2
finance/money	0	0.0	0	0.0	0	0.0
friends	2	0.2	9	0.9	3	3.2
gift/new object	0	0.0	2	0.2	0	0.0
health status	3	0.3	9	0.9	1	1.1
hobby/talent/ability	2	0.2	1	0.1	0	0.0
holiday	2	0.2	4	0.4	0	0.0
hospitalization	6	0.6	46	4.6	13	13.7
independence	0	0.0	1	0.1	0	0.0
life	2	0.2	4	0.4	0	0.0
lung transplant	1	0.1	11	1.1	2	2.1
medical procedure	7	0.7	37	3.7	14	14.7
medical test/exam	0	0.0	5	0.5	1	1.1

missing an event/activity	1	0.1	4	0.4	0	0.0
mistake/doing something wrong	0	0.0	0	0.0	0	0.0
other	0	0.0	0	0.0	0	0.0
group/organization awareness						
other illnesses	4	0.4	10	1.0	2	2.1
Outside communication	9	0.9	26	2.6	0	0.0
pain	2	0.2	24	5.6	6	9.0
pet/animal	0	0.0	3	0.3	0	0.0
physical appearance	3	0.3	3	0.3	0	0.0
pop culture	14	1.4	4	0.4	1	1.1
psychological diagnosis	0	0.0	0	0.0	0	0.0
punishment	0	0.0	0	0.0	0	0.0
putting self-down/insults to self	0	0.0	1	0.1	0	0.0
quote	0	0.0	1	0.1	0	0.0
religion	2	0.2	17	1.7	0	0.0
research	0	0.0	0	0.0	0	0.0
participant						
romance	2	0.2	7	0.7	0	0.0
salutation	3	0.3	1	0.1	0	0.0
sarcasm	1	0.1	0	0.0	0	0.0
school	17	1.7	55	5.5	8	8.4
sick	20	2.0	104	10.3	5	5.3
sleep	0	0.0	1	0.1	0	0.0
social event	0	0.0	0	0.0	0	0.0
summer break	0	0.0	3	0.3	0	0.0
technology	0	0.0	2	0.2	1	1.1
thankfulness	6	0.6	2	0.2	1	1.1
therapist	0	0.0	0	0.0	0	0.0
trauma	0	0.0	0	0.0	0	0.0
travel/new place	1	0.1	2	0.2	0	0.0
treatment	38	3.7	77	7.7	14	14.7
weather	0	0.0	2	0.2	0	0.0
weight general	3	0.3	5	0.5	1	1.1
well being	8	0.8	18	1.8	0	0.0
winter break	0	0.0	0	0.0	0	0.0
wish	1	0.1	7	0.7	0	0.0

Table 11

*Percentage of each Type of Social Support Provided for each NonCF-related Topic*

NonCF-related topics	n of companion support posts	% of total companion support	n of emotional support	% of total emotional support	n of inform support	% of total inform support
award/recognition	1	0.1	3	0.3	0	0.0
birthday	16	1.6	12	1.2	0	0.0
busy-ness	0	0.0	0	0.0	0	0.0
career/work	15	1.5	7	0.7	1	1.1
CF diagnosis	0	0.0	0	0.0	0	0.0
CF symptoms	0	0.0	0	0.0	0	0.0
CFfone website	92	9.0	36	3.6	4	4.2
Clinic	0	0.0	1	0.1	0	0.0
College	1	0.1	5	0.5	0	0.0
cure	1	0.1	3	0.3	0	0.0
day of the week	18	1.8	5	0.5	0	0.0
death	5	0.5	20	2.0	0	0.0
demographics	108	10.6	8	0.8	0	0.0
disease awareness	1	0.1	3	0.3	0	0.0
dislikes	7	0.7	30	3.0	0	0.0
eating	31	3.0	9	0.9	2	2.1
emotional state	15	1.5	59	5.9	2	2.1
exercise	6	0.6	12	1.2	1	1.1
extracurricular activities	72	7.1	56	5.6	1	1.1
facts and quizzes	8	0.8	0	0.0	1	1.1
family	44	4.3	36	3.6	1	1.1
finance/money	0	0.0	0	0.0	0	0.0
friends	22	2.2	38	3.8	2	2.1
gift/new object	18	1.8	3	0.3	0	0.0
health status	1	0.1	2	0.2	0	0.0
hobby/talent/ability	15	1.5	6	0.6	0	0.0
holiday	62	6.1	11	1.1	0	0.0
hospitalization	1	0.1	0	0.0	0	0.0
independence	0	0.0	0	0.0	0	0.0
life	16	1.6	8	0.8	1	1.1
lung transplant	0	0.0	0	0.0	0	0.0
medical procedure	1	0.1	1	0.1	0	0.0
medical test/exam	0	0.0	0	0.0	0	0.0
missing an event/activity	0	0.0	1	0.1	0	0.0

mistake/doing something wrong	5	0.5	3	0.3	0	0.0
other group/organization awareness	0	0.0	0	0.0	0	0.0
other illnesses	0	0.0	14	1.4	3	3.2
Outside communication	48	4.7	54	5.4	0	0.0
pain	1	0.1	4	0.7	0	0
pet/animal	8	0.8	8	0.8	1	1.1
physical appearance	9	0.9	18	1.8	2	2.1
pop culture	113	11.1	17	1.7	0	0.0
psychological diagnosis	0	0.0	0	0.0	0	0.0
punishment	0	0.0	4	0.4	0	0.0
putting self-down/insults to self	2	0.2	6	0.6	1	1.1
quote	33	3.2	7	0.7	0	0.0
religion	24	2.4	22	2.2	0	0.0
research participant	0	0.0	0	0.0	0	0.0
romance	27	2.7	89	8.9	1	1.1
salutation	105	10.3	4	0.4	1	1.1
sarcasm	0	0.0	1	0.1	0	0.0
school	76	7.5	97	9.7	0	0.0
sick	13	1.3	38	3.8	0	0.0
sleep	4	0.4	0	0.0	0	0.0
social event	9	0.9	13	1.3	0	0.0
summer break	2	0.2	3	0.3	0	0.0
technology	9	0.9	7	0.7	2	2.1
thankfulness	0	0.0	1	0.1	0	0.0
therapist	1	0.1	6	0.6	3	3.2
trauma	3	0.3	20	2.0	0	0.0
travel/new place	17	1.7	7	0.7	0	0.0
treatment	9	0.9	8	0.8	0	0.0
weather	6	0.6	0	0.0	0	0.0
weight general	0	0.0	1	0.1	1	1.1
well being	57	5.6	26	2.6	1	1.1
winter break	4	0.4	0	0.0	0	0.0
wish	1	0.1	3	0.3	0	0.0

Table 12

*Top 3 Most Frequent Topics of Discussion per Each Type of Social Support*

	Companionship n	Emotional n	Informational n
CF-related	n=163	n=432	n=68
1.	CF diagnosis	Sick	CF symptoms
2.	Treatment	Treatment	Treatment
3.	Sick	CF symptoms	Medical procedure
NonCF-related	n=822	n=550	n=25
1.	Pop culture	School	CFfone website
2.	Demographics	Romance	Therapist
3.	Salutation	Emotional state	Other illness
CF context Females	n=175	n=437	n=69
1.	CF diagnosis	Sick	CF symptoms
2.	Treatment	Treatment	Treatment
3.	Pop culture	CF symptoms	Medical procedure
NonCF context Females	n=819	n=560	n=20
1.	Salutation	School	CFfone website
2.	Demographics	Romance	Therapist
3.	Pop culture	Emotional state	Other illness
CF context Males	n=5	n=6	n=2
1.	CF diagnosis	Treatment	-
2.	-	-	-
3.	-	-	-
NonCF context Males	n=30	n=12	n=4
1.	Pop culture	Extracurricular activities	Technology
2.	CFfone website	CFfone website	-
3.	Salutation	Romance	-
CF context Younger	n=119	n=300	n=43
1.	Treatment	Sick	CF symptoms
2.	CF diagnosis	Treatment	Treatment
3.	Sick	CF symptoms	Medical procedure
NonCF context Younger	n=627	n=401	n=14
1.	Salutation	School	CFfone website
2.	Pop culture	Romance	Friends/Emotional

CF context Older	3.	Demographics n=61	Emotional state n=143	state Other illness n=28
	1.	CF diagnosis	Treatment	Hospitalization
	2.	Treatment	Sick	CF symptoms
NonCF context Older	3.	School n=222	CF symptoms n=171	Treatment n=10
	1.	Demographics	Romance	Therapist
	2.	Pop culture	Outside communication	Technology
	3.	Cffone website/Salutation	School	-

Note. (-) there is no other topic category with more than 1 observation.

Table 13

*Characteristics of Appreciative Responses*

Appreciative responses	# of responses	% of total postings <sup>a</sup>
Total number of postings	191	5.7
Females	186	5.5
Males	5	0.1
Younger	132	3.9
Older	59	1.8
CF context	67	7.0 <sup>b</sup>
NonCF context	119	4.9 <sup>b</sup>

<sup>a</sup> percentage of total postings [total main posts (n=1024) + total responses by others (n=1978)+total responses by main posters (n=354)= 3356]; <sup>b</sup> percentage of total posting per context type



Figure 1. A snapshot of Cffone adolescent's wall in which users can post a main post or a response post. Main posts and responses to main posts are organized in chronological order.

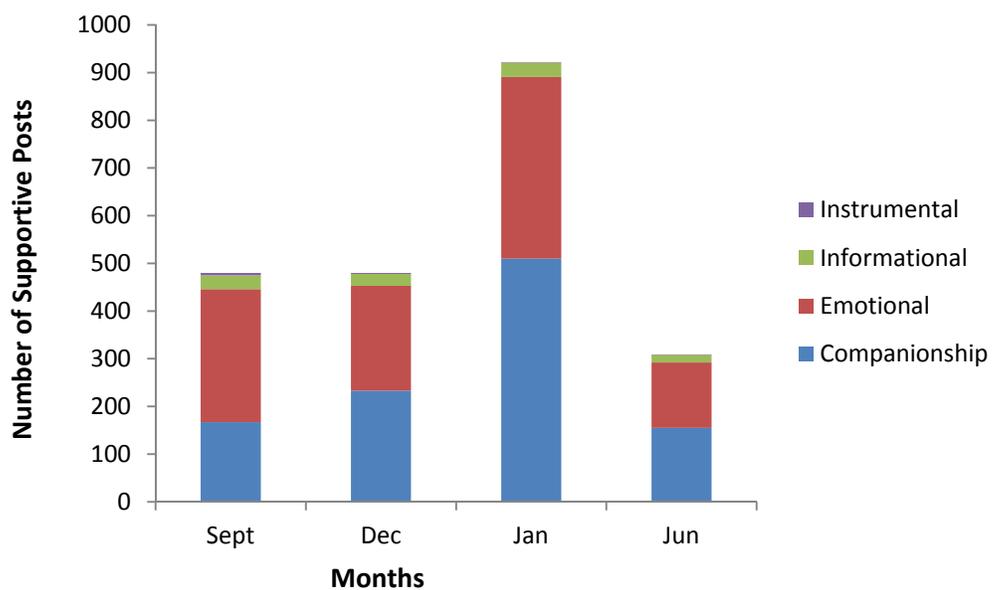


Figure 2. Frequency of each type of social support provided by months

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## Appendix

There was a coding scheme for the different types of social support and topics of discussion that occurred on the Cffone™ adolescent wall. In addition, there were other codes created to describe the type of post and the user making the post. Posts could be coded with more than one category of each scheme. Each category is discussed further with an example to highlight its importance and exclusivity from other categories within the same scheme.

Table A1

### *Social Support Categories*

Category	Definition	Example posting
Chatting	About ordinary, everyday happenings.	"*yawn* good morning (:"
Groupness	The feeling of being part of a group	"hi!we all missed u!"
Humor/Sarcasm	Funny and causing laughter	"right, because the workout is completely worthless without the eye candy. i completely understand :p lol."
Sympathy	Feeling sorry about a situation	
Caring	Emotional expression that someone is valued and important including taking time to listen to them, or inquiring/showing interest that you want to know what is wrong	"aww text me if you wanna talk."
Affirmation	Agreeing with a comment/remark	"^i agree! i mean seriously, they could have dropped the ball on purpose too!"

Encouragement	Cheering, providing motivation	"good luck, you'll do great!!! :)"
Praying	Seeking spiritual assistance	"i'll be praying for you."
Understanding	Can relate to a situation	"i took prendisone for 3 years trust me i know how u feel"
Advice	Suggestions	"try to set a goal for yourself for everytime you do your meds find something yummy to eat or fun to look forward to after they're don!"
Referral	Recommending other resources	"i suggest that if it doesn't go away in the next few hours that you should have it looked at."
Teaching	The provision of knowledge	"im in 3-4 times a years its not bad. heads up depending on what you have they will probably come in every other day to take blood"
Instrumental	Reference to the provision of tangible aid	"hopefully sending pizza to one of my [Cffone] friends today! :)"

Table A2

*Topic Categories*

Topics	Definition	Example posting
award/recognition	The receipt of an award or recognition for an accomplishment	"i won the most improved" for the guys. my first trophy"
Birthday	posts about birthdays	"happpppyyyy birrrttthdaayyy!!!"
busy-ness	Posts about having a lot to do or not having enough time	"lots of stuff to do...better get started a.s.a.p!!!"
career/work	Employment or related to future career/work	"i really need to find a job :/"
CF diagnosis	posts about gene type, about receiving CF diagnosis, about having CF, disclosure	"i have the cf type called... delta f508"
CF symptoms	posts about coughing, losing weight, shortness of breath	"cough cough cough cough cough i hate you.."
CFfone website	Post about CFfone and/or the users which can be positive and/or negative), including doing something to CFfone wall, being new to CFfone, or being away from CFfone	"wow nothing has changed since last i've been on. everyone's still having ups and their downs but just doing great! hope everyone is doing ok just here to let you know how happy i am to be back online again!"
Clinic	Posts about clinic visits, including the routine and doctor's orders	"help had a terrible clinic visite today!:("
college	Posts about college	"i got ym very first college acceptance letter!!!!!!! so freaking happy!!!!!!"

		Ahhhhhhhhh”
Cure	Posts about a cure for CF	“i pray to god every night there will be a cure for cf one day. some day. i hope he's answering our prayers.”
day of the week	Posts about a day of the week	“friday! gotta love it!”
Death	Posts about own or other’s death or the concept of death	“i've always wondered what its like in heaven too!”
demographics	Sharing demographic information, including age, location of residency, year in school	“hey i am [Sally]! i am 14! hope you like it here to!”
disease awareness	Posts about activities bringing awareness to CF and other diseases, including presentations, walks, fundraisers	“it is my personal goal to get travis fimmel to come to the 2013 cf walk....i will make it happen!”
Dislikes	Posts about not liking or hating things or people	“i want to slap people who smoke in the face.i hate it.”
Eating	Posts related to eating or food	“eating a breakfast sandwich at 8:26...yeah. completely normal. (:”
emotional state	Posts in which users states how they are feeling	“not feeling so happy...”
Exercise	Posts about doing exercise or working out	“got to finally workout today “
extracurricular activities	Activities that occur outside of school hours including sport practices, camp, church activities, chores, community services	“youth group 2night! ;) yay!! “

facts and quizzes	Posts about factual information or trivia questions	"wow i read on a cf forum that it's possible that albert einstein could've had a very minor case of cf"
Family	Posts about parents, sibling, and other family members	"my mother doesnt understand me"
finance/money	Posts about finances or money	"we have to come up with \$1000+!!!"
Friends	Reference to any type of friends, friends from school, community, church, or Cffone	"hanging with my bestie :) "
gift/new object	Receiving a gift or a new object from others or the user him/herself	"got a brand new, hard cover sketch book ! :d"
health status	Posts about health status, including feeling worse,feeling better, or PFT	"pfts went down 6%"
hobbies/talent/ability	Posts about the user's hobbies, talent, or abilities	"drawing the mona lisa...as a skeleton (;"
Holiday	Posts related to a holiday (e.g. Christmas, Hanukah, Valentine's Day)	"happy new years my fellow cfers!"
hospitalization	Posts related to hospitalization, including being admitted or being discharged	"been in the hospital for a week now.....im so glad i actually like my doctors and nurses or i would be totally bummed :/"
independence	Posts about being independent and not relying on others	"i plan on by january of next year i will be having a vehicle and be driving to school and also having a job"

Life	Posts about life in general	"i'm trying to make my life more eventful and fun, so that it doesn't feel like that evryday! :)"
lung transplant	Posts about lung transplant including getting assessments for or being place on the wait list for lung transplant	"the doctors want me to be put on the waiting list to get a lung transplant. im so scared and stressed."
medical procedure	Posts about medical procedures, including minor and surgical procedures	"hey guys, so next monday i'm getting a picc line in."
medical test/exam	Posts about medical test or exams	"got the ct scan...now what?"
missing an event/activity	Posts about not be able to attend an event or activity	"missed the christmas party at church cuz im sick."
mistake/doing something wrong	Posts in which user is aware that he/she has done something wrong	"i ran into a curb today, not paying attention and turned to late"
other group/organization awareness	Posts about other group or organization awareness	"i also raised about \$100 for the make a wish foundation. great night."
other illnesses	Posts about other illnesses	"grr i reeaally hate allergies!! not feeling so good now because of them! :p"
outside communication	Posts about other means of communication, outside of Cffone	"had fun texting u tonite text me tomorrow when u can."
Pain	Posts about pain, including feeling and relieving pain	"dude i cant stop coughing and it really hurts my chest ;{"
pet/animal	Posts about pets or	"my puppy peed on my bed :/"

	animal	
physical appearance	Posts about physical appearance including the enhancement or defect of appearance	"im so happy im almost off my prednisone but now im like fat :("
pop culture	Posts about popular movies, songs, fashion, celebrities	"i honestly think soon rihanna may either follow me, retweet me, message me or at least notice me on twitter soon, when that day comes expect me to be in the hospital due to heart attacks."
psychological diagnosis	Posts about psychological diagnosis including actually having or thinking to have a disorder	"i swear i might be bipolar."
punishment	Posts about receiving or being punished	"i was grounded and i didn't have my phone. -_-"
putting self-down/insults to self	Posts in which the user insults him/herself	"felling like i am a worthless person :/"
Quote	Posting a quote/phrase said by someone else	"quote of the day: dont tell me the sky is the limit when there are footprints on the moon."
Religion	Posts about religion but does not include the provision of prayer	"all of you are beautiful, strong, and wonderfully made in god's eyes!! god has a plan for all of us! sometimes we have to go through trials, emotional and physical pain, and fear to follow in his plan for all of us!!"
research participant	Posts about participating in a research study	"went to the cf clinic today for a study. anyone else on ptc124??"
Romance	Posts about liking or having a crush or being in/breaking up from a romantic relationship	"i'm making an effort to talk to my crush...he looked at me a few times in spanish and our eyes met (:"

Salutation	Greetings and goodbye	"goodnight cffone zzzzz."
Sarcasm	Posts that are sarcastic	"great.. my dads mad... joy. -_-"
School	Posts about school related issues, including tests, assignments, grades, classmates, homeschooling, graduation, teachers	"high school is rough, but when you're a junior with cf, it's even more rough"
Sick	Posts about not feeling well	"im sick too. we can be sick together!"
Sleep	Posts about not getting enough of sleep or sleeping too much or sleeping later or sleeping early	"i haven't slept well in a week cuz i keep feeling like my room in 9,000 degrees when its only 75"
social event	Posts related to social events including parties and school dances	"16th birthday party 2night!!!!!!!!!!!!!!"
summer break	Posts about summer activities or thoughts	"why is summer so short , i wish school was this long and summer was the school year. u no wat i mean"
technology	Posts about technology, including electronic devices	"had a horrible virus on my computer."
thankfulness	Posts about being thankful	"what helps me when im sad is to think of all the things im thankful for."
Therapist	Posts about regarding services from therapists, including counselor, psychologist, psychiatrist	"i've been seeing a therapist for a long time. it's very helpful! good luck! :)"
Trauma	Posts about traumatic events due to mother nature or a violent act	"horrible, horrible day, i got robbed today, i was home alone with my little brother and sister. and they just broke in."

travel/new place	Posts about traveling or being in a new place	"in maryland... first time traveling on my own"
Treatment	Posts about treatment including medications, adherence, burdensome, doing the vest, IV antibiotics	"i take albuterol, saline, pulmozyme, cayston, tobi, zazythromycin, source cf, vitamin k, ursodial, omeprazole, nadolol, lantus insulin, and novolog insulin! :p i think and hope that's it! lol!"
Weather	Posts about the weather and the change of season	"snowing for the first time all winter!!!"
weight general	Posts about weight but not as a symptom of being sick	"i've seen so many how to lose weight commercials!! i wish they would show a how to gain weight comercial!!"
well being	Posts about how the user is doing at the current time of response including response to the question "How are you?"	" i'm bored!!!"
winter break	Posts about activities or plans for winter break	"thank god it's finally christmas break!!!!!"
Wish	Posts about users' wishes or wishes made to Make-a Wish foundation	"i'm really hoping to have it [PICC line] out by new year's eve. #wishfulthinking."

Table 3A

*Post Characteristics Categories*

Category	Definition	Example posting
NonCf-related topic	Topics not about or associated with CF	"got a black eye at my softball game last night. :(9"
CF-related topic	Topics about or associated with having CF	"i swear if i have to take another dose of prednisone im gonna die. :("
Main post	A post that initiates a thread	Coded based on the organization of the thread not on content of the post
Response	A post that responds to a main post or another response	Coded based on the organization of the thread not on content of the post
Appreciative response	Being thankful or grateful for a response	"awww thank you everyone!! :d"
Main poster response	A poster that responds to the thread that was initiated by him/herself	Coded based on the organization of the thread not on content of the post
Username	The website username that posted the message	Coded based on the organization of the thread not on content of the post