E-PATIENTS AND CAREGIVERS COPING WITH CYSTIC FIBROSIS: THE
RELATIONSHIP BETWEEN RELATIONAL SATISFACTION
AND ATTITUDES TOWARD GROUPS, LONELINESS,
AND SOCIAL SUPPORT ONLINE

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E-PATIENTS AND CAREGIVERS COPING WITH CYSTIC FIBROSIS: THE RELATIONSHIP BETWEEN RELATIONAL SATISFACTION AND ATTITUDES TOWARD GROUPS, LONELINESS, AND SOCIAL SUPPORT ONLINE

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ABSTRACT

This study contributes to the growing focus on online support groups and computer mediated communication by examining a unique population of individuals inflicted with, or caring for someone inflicted with, the genetic disorder of Cystic Fibrosis. Although significant advances have been made in the treatment of this disease over the last 30 years, recent findings have found that face-to-face interactions between individuals with the disease should be avoided. With this understanding, the current study focuses on this population in an online social support group environment. The theoretical framework was drawn from Schutz’s (1966) Interpersonal Needs Theory, as applied to the group setting. The first goal of the study was to determine the relationship between Relational satisfaction, attitudes toward support groups, loneliness, and social support. The second goal of this study was to expand our knowledge by examining these relationships for the first time in an online setting. Results from the study showed a positive relationship between relational satisfaction, attitude toward groups and social support, while the data showed a relationship in a negative manner between relational satisfaction and loneliness. The study adds to the rapidly growing body of research focusing on online support groups and computer mediated communication.
ACKNOWLEDGMENTS

"Without faith, hope and trust, there is no promise for the future, and without a promising future, life has no direction, no meaning and no justification."

Adlin Sindair

It was not until I had the opportunity to meet the faculty of the School of Communication at The University of Akron, that I was exposed to the possibility of real direction for my life. My original intent upon returning to school was only to finish my Bachelors Degree. However, because of the inspiration, expertise, and guidance that I received upon each encounter with the faculty, I am now going on to pursue a Ph.D. There are no words that can express the gratitude I have for everyone I have been introduced to in the past two years. They have helped me as I worked on this thesis, but they have also helped with guidance for so much more. Dr. Carolyn Anderson, my thesis advisor, has been instrumental in helping me with the entire process of writing a thesis. However, her guidance, advice, and ability to go from instructor to mentor instantaneously, has kept me on track through this process and in life. Dr. Heather Walter has also set the foundation for my love of this field and the processes involved. She has kept me grounded and has listened patiently more times then her scheduled allowed. I am sincerely grateful. I would also like to extend sincere thanks to Dr. Young Lin, who taught me more than he will ever realize and who has been patient with me throughout the thesis process.
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Correlations between relational satisfaction and attitudes toward Groups, social support and loneliness
CHAPTER I
INTRODUCTION

The stimulus for conducting this study was the population of individuals specifically inflicted with the disease Cystic Fibrosis (CF) and their caregivers. Cystic Fibrosis, a life-threatening genetic disease, currently inflicts about 30,000 people in the United States, 70,000 people worldwide. Most of the individuals currently living with CF were diagnosed near or within a few years of birth. There is currently no cure for this disease. The current life expectancy for individuals inflicted with CF is 36.5 years, which is an advancement from the 1955 expected age of only six or seven years (About Cystic Fibrosis Section, 2006). In addition to the advances that are being made medically to treat this disease, at the same time advances are also being made in the communication aspect of helping patients and caregivers deal with stress, coping, and day-to-day needs of the individuals involved with or inflicted with this disease. As recently as the mid 1980’s, camps were created for children with Cystic Fibrosis to attend and be able to socialize with others experiencing the same symptoms. More recently, it was discovered that social interaction was leading to cross-infection between children. This development and better understanding of the disease has led to limitations of socialization that individuals inflicted with Cystic Fibrosis can have with other individuals with the same disorder.
This situation raised the question examined in this study concerning relational satisfaction. When individuals can not communicate face-to-face do they perceive relational satisfaction in the online groups? The theoretical framework used in this study to examine this question is Schutz’s (1966) Interpersonal Needs Theory. This theory states that individuals have social needs that can only be met by other people. These needs, according to the theory, are inclusion, control, and affection. “An interpersonal need is a requirement to establish a satisfactory relation between the individual and his human environment” (Schutz, p. 16). This study is interested in assessing if the perception of individuals coping with Cystic Fibrosis using an online support group report having these needs met.

This study examines online support groups by specifically focusing on support groups aimed at E-Patients with Cystic Fibrosis and also at the caregivers involved with loved ones inflicted with the disease. Many of these caregivers are parents and primary custodians for individuals with CF. Because of the potential of cross-infection and contamination being higher with exposure of individuals with Cystic Fibrosis to others also diagnosed with the same condition, the ability to participate in face-to-face support groups with others facing the same struggles is not possible for the majority of the patients affected with this condition. As a result, online support groups become an important, often only alternative for any support among individuals to communicate with others experiencing the same issues.

This study begins by examining the theoretical framework outlined by Shutz, (1966). It then traces a brief history of Cystic Fibrosis and the importance of online support groups to individuals with this condition. Following this, the study explores the
history of literature and research on social support, attitudes toward working in groups, loneliness, and the perceived relational satisfaction of those participating in the support group. Finally, the study investigates the relationship of these constructs by specifically focusing on Internet websites designated to the topic of Cystic Fibrosis and supporting patients through information, bulletin boards, blog posts and links. These sites provide assistance, education and support for individuals with Cystic Fibrosis and also to friends and family members of those related to someone with the disease. 

For the purpose of this study it is important to define the key terms present throughout the analysis. These definitions will provide an outline and context of the material gathered. Online support group is defined as any publicly accessed website that provides information about CF and also an avenue for individuals to discuss ideas, concerns, and questions relating to the disease. These sites generally use message boards, which are messages generated most often by one individual. The message is posted either chronologically or as part of a thread which is an addition to an earlier post. Other users can read these messages and respond to or print the message. In some cases, the user can also privately respond to the person generating the message through a private e-mail address. Caregiver is defined as any individual providing physical assistance, psychological support, or friendship, to another individual with CF.

The current study sets a foundation for future research in the development and improvement of online support group data that deal with Cystic Fibrosis. Scarce research has been done that focuses on this specific unique group of individuals. Providing a foundation for further studies will greatly enhance the understanding of the communication, use, and perceptions involving users of these CF websites. Since
physical contact and even face-to-face interaction need to be limited, the goal of this study is to determine the relational satisfaction found for patients and caregivers when communicating in the medium of online groups.
CHAPTER II
LITERATURE REVIEW

Thoretical Framework

Individuals have needs, the need for sustenance, the need for feeling safe, and among others, the need for social interaction. Schutz (1966) focused on needs from just the social aspect and found that individuals also have specific social needs that include the “situations or conditions that can only be met by other people. This is what draws us to one another in groups to live, play, and work” (Keyton, 2006). The social needs established through Schutz’s (1966) work include, the need for inclusion, the need for control, and the need for affection. The need for inclusion is the drive that motivates individuals to establish and maintain relationships. From acquaintances to intimate relationships, these connections help the individual feel important in the roles they fill. The need for control affects many aspects of life. In general, it is the need to feel as if the individual has a say in what happens in life. The final need, affection, is the need to be able to feel as if an individual is likable, and also the need to project affection onto other individuals. (Schutz, 1966). “Nonfulfillment of an interpersonal need leads to mental (or interpersonal) illness and sometimes death” (p. 16). Schutz describes these needs as being paramount to individual growth, development and satisfaction. Although, originally these constructs were applied to interpersonal communication. More recently, these constructs
have been applied to group settings and the dyadic relationships formed within them. (Braithwaite, Waldron & Finn, 1999; Keyton, 2005).

In social support settings, these needs can often be the reason individuals seek support for the situations they face in life. Social support revolves around shared experiences, usually stressful, that individuals unexpectedly find themselves in, disease, addiction, and social life changes are a few examples of these situations. “These groups are an attempt by people with mutual needs to exert control over circumstances that affect their lives” (Braithwaite et al., 1999).

Study Variables

This study looked at several variables used in communication studies in the past, most applied to face-to-face situations. This study examines past studies, both face-to-face and in computer mediated situations, and also examines the possible outcome of combining several variables that have not been used in the same study in the past.

Relational satisfaction

Satisfaction in the small group context is also a large focus of attention for researchers. The overall satisfaction of group members can affect many factors within the group, such as the success or failure of accomplishment of goals and member contribution and loyalty to a group. In social settings, satisfaction can influence continued participation, the overall climate of the group, and on an individual level, what each person actually gets out of the group setting (Anderson & Martin, 1995; Riddle, Anderson, & Martin, 2000).

Recent trends in small group research have shifted focus from classroom or laboratory group interaction to bona fide groups in natural settings. Satisfaction in these
settings has long been of interest to researchers; Keyton, in a 1991 study, reviewed an abundance of work on group satisfaction and found that the construct should be broken down by situation. “Three major variables were identified that could be operationally defined and that account for satisfaction; these three variables are status consensus, perceived progress toward group goal, and perceived freedom to participate” (Keyton, 1991, p. 201).

In addition, other studies have linked job performance, quality of idea-generation, and the cohesiveness of a group to the overall satisfaction of group members (Flanagin, Park, & Seibold, 2004; Jackson & Poole, 2003; Rozell & Gundersen, 2003).

Overall, these studies all focused on satisfaction as playing a major role in successful groups. Some of these studies have looked at computer-mediated-communication; however, the majority of small group research is largely devoted to face-to-face communication. The current study investigated the relational satisfaction of participants using the online medium in groups. Participants were asked questions pertaining to their perception of satisfaction to the online site they use, and looks for relationships with that variable and others, one being attitudes toward groups.

Attitudes toward groups.

Attitude, when defined as a predisposed feeling about a person or thing, can dictate much about how an individual communicates, especially in a group setting (Azjen, & Fishbein 1980). Studies have found that although individual differences affect how members work together in groups, attitudes about groups formed from prior experiences affect how individuals approach new groups and group members and how they communicate with them. (Anderson, Riddle & Martin, 2001, p. 242)
Being able to tie this information in with the use and satisfaction of users of a support group is an interesting concept.

The growth of research on online support groups has looked at many group aspects; however little research has tied empirical work and theory built on face-to-face groups with the similar features present in computer-mediated-groups. This study will look at satisfaction within an online CF support group, preconceived attitudes toward working in groups and also at loneliness as a factor contributing to or resulting in the use of online support groups. Based on this information, this study will examine the following relationship:

H1: Relational satisfaction will be related to attitudes toward online support groups in a positive manner.

Social Support

The need for social support is well documented and understood for people dealing with stressors in their lives. Coping during times of stress plays an integral part in that process. According to duPre, “Coping strategies and social support often look very much alike” (2005, p. 174). Coping falls into one of two categories, according to research findings. The first category is problem solving efforts that focus on changing what can be changed. The second category is the emotional adjustment that focuses on adapting to what can not be changed (Albrecht & Adelman, 1987; du Pre, 2005; Wright, 1999). Where individuals turn for support and how individuals cope with situations perceived as stressful is the focus of social support. The definitions of social support vary but focus on individual’s situations or on the feelings of need and esteem support gives an individual. One well-established definition by Albrecht and Adelman in 1987 states that it “refers to
verbal and nonverbal communication between recipients and providers that helps manage uncertainty about the situation, the self, the other or the relationship and functions to enhance a perception of personal control in one’s life experience” (p.19). The complexity of how this communication occurs and to what extent it is successful is the focus of many studies. Researchers have focused on face-to-face support groups and, more recently, with online support groups dedicated to a variety of issues. Study results have found that any type of support system is essential for a quality life in individuals (Albrecht & Adelman, 1987; Cohen & Wills, 1985; du Pre, 2005). Albrecht and Adelman (1987) state:

Social support is a topic with compelling appeal. To put the issue simply: Studying the ways human relationships relate to physical and emotional health has real social and theoretical value. Certainly the complex findings in this area are creating ways we can all live richer and longer lives. (p. 18)

Communication researchers agree that the foundation of any support is communication. Albrecht and Adelman (1987) explain the importance of this by stating:

The communication of help is a symbolic activity embedded in personal relationships. Conceiving of social support from a communication perspective casts it as a transactional, symbolic process of mutual influence occurring between two or three individuals that alters their affective, cognitive, or behavioral states. (p. 20)

With changes and advancements constantly being made to digital communication, the realization and understanding of these concepts is a prospect becoming easier to obtain. Combined with the growth and ability of people of every demographic to be able to access these outlets, support is easier then ever for people with the rarest of
circumstances to be able to obtain social support from people experiencing similar circumstances via the Internet.

**Online Social Support**

The research currently available pertaining to computer mediated communication is not only vast but also continues to gain attention. The studies cover a range of issues including the negative and positive aspects of the anonymity of online communication, the likelihood of false information being given in communication transactions online and also the use of emoticons, the symbols created to reflect emotion, to produce nonverbal cues in a nonverbal environment (Barak, 2007; Beder, 2005; Turner, Grube, Meyers, 2001). The focus specifically on online support groups is also growing. In the 2003 publication of *Group Communication in Context*, a chapter is dedicated to the topic of online support groups. It states that, “all Internet support groups are not created equal: They differ from one another in their membership, the ways that they provide support to their members, and how they affect and are affected by their environment” (Frey, 2003, p. 247).

Several studies have focused on different types of online support groups. Included have been studies dedicated to online support groups for individuals with breast cancer, HIV-aids, Alcoholics Anonymous, and a specific site dedicated to support for individuals contemplating suicide (Barak, 2007; Braithwaite, Waldron, & Finn, 1999; Reeves, 2000; Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2006). Each of the studies focused on different aspects of communication within these support groups such as disclosure issues, the impact of use of an online support group, emotional support, and the types of support perceived to be achieved in these participations. Warnings of
extensive reliance upon and also of the negative aspects of online support have also been studied. The language used and the practice of flaming, which is the negative, often abusive, attempt to discredit an individual does occur (Caplan & Turner, 2005). In addition, the possibility of imposters claiming illness in a support situation occurs. One example is Munchausen syndrome, a “virtual” version of mental illness occurs when people fake an illness to get medical treatment. With online support groups the goal is to be the center of attention (National Council for Reliable Health Information, 2000). Other communication challenges researched in computer mediated support groups include stress and coping strategies, and communication competence (Wright, 1999; Query & Wright, 2003).

A 1999 study by Braithwaite, Waldron, and Finn on social support in computer mediated groups for people with disabilities examined many of the benefits of online support groups focusing on the messages exchanged between the members of the groups. The researchers compared these finding with the Social Support Behavior Codes framework developed by Cutrona and Suhr in 1992. Their findings supported positive relationships between online support and the supratypes illustrated in the behavior codes. The types of codes outlined types of support, categorizing them in to five supratypes including: “informational support, tangible, esteem, emotional, and social network support” (Cutrona & Shur, 1992, p. 155).

The Braithwaite et al. (1999) study highlighted several key elements beneficial to online support for people with disabilities. These elements included the discussion of mobility and access issues that some people with disabilities may have, potentially, physical and communication-related barriers may be eliminated through online
interaction. In addition, the possible number of participants is vast, the availability of information to members and non-members is also large, and additionally the time delay of messages and how this inspires more thought out responses and potentially more directed communication. The Braithwaite et al. (1999) study states that computer mediated communication “may result in more time to think about support requests before replying. Relieved of the need to respond immediately, support providers may be able to provide better or more thoughtful advice” (p. 129). More recent studies have focused on the emotional messages relayed in CMC support groups. A 2005 study by Beder highlighted the term cybersolace as being “an interaction between and among individuals that is focused on offering solace using various electronic technologies” (p.355). The authors go on to state that cybersolace is “technology built on emotion and caring” (p 356).

A longitudinal two and a half year ethnographic study by Maloney-Krichmar and Preece (2005) observed a well-established online support group for a very specific purpose. This support group, started in 1997, uses a very simple platform with very limited options, and one that would seem archaic by many of the sites available presently. However, in spite of the design of the site, the site has an established faithful group of participants and maintains success. The researchers of this line of research contribute the success of the site to a number of factors including the specificity of the site’s purpose.

The site examined is named Bob’s ACL (Anterior Cruciate Ligament) WWW Board or the Kneeboard. ACL is a specific knee injury so participants to the site all have a specific commonality. This is different from other support group sites that have a more varied theme such as alcoholics anonymous, although participants to that site may all
have alcohol related issues, the circumstances and issues may be varied. The study also looks at group roles within the kneeboard site, as well as a variety of other issues such as group norms. The authors explain that this process has traditionally been used in face-to-face groups to “identify the norms and values of a group and the predominant forms of behavior” (Maloney-Krichmar & Preece, 2005, p. 203). The study classified many of the roles taken by individuals on the Kneeboard. These constructs were similar to the classifications defined in face-to-face groups. This, in addition to the strong group norms displayed on the site, was sited as another reason for the overall success of the Kneeboard site. Interestingly, the Maloney-Krichmar & Preece (2005) study provided fodder for many aspects of online support studies.

Other important research into the field of online support groups includes the study of applying theory to computer-mediated comforting communication. For example, a study conducted by Caplan and Turner (2005) focused on the positive and negative attributes to comfort communication. These authors compared their findings to past research done in face-to-face support situations and have found similarities in both areas. Specifically, they found “one group of people that may especially benefit from reduced social risk associated with online support are people suffering emotional distress surrounding stigmatized conditions such as HIV, AIDS, cancer, eating disorders, physical disabilities, and even old age” (Caplan & Turner, 2005). Another study focuses on fitting a patient with the right type of online support group for that person. The research examined the needs of the individual patient in reference to the type of support offered by different sites. Newly diagnosed patients needed more interaction while patients with
non-severe illnesses could benefit from using primarily information-based groups. (Turner, Grube, & Meyers, 2001; White & Dorman, 2001).

The research highlighted above make advancement in research a priority on the topic of online support. It is essential that researchers recognize issues and assists in the development of guidelines for communicating in online support groups and also advances the understanding of communication within computer mediated communication (CMC). Looking for information to contribute to the growth of this type of communication research, the current study looked at the following:

H2: Relational satisfaction in online support groups will be positively related to social support for patients and caregivers using online support groups focused on Cystic Fibrosis.

Loneliness

Loneliness can be both a symptom of the need to seek online support groups and a result of the prolonged use of online support. Theoretically, patients with CF and caregivers of those patients could be more susceptible to loneliness due to the inability to communicate in face-to-face situations with others with Cystic Fibrosis. Kraut et al. (1998) have studied loneliness specifically with those using the internet for communication and support. A study in 1998 found a negative effect of online communication on social involvement and psychological well-being in users of CMC (p. 1025). However, subsequent studies have resulted in more positive outcomes to users of online communication. The Kraut et al. (1998) study showed as more and more people use online communication, the more it is replacing other forms of communication (p. 50). Other studies have grown from the initial studies about internet use and an individual’s
psychological health. Recent studies examined loneliness and Internet use by looking at other variables associated with both constructs. In a 2002 study, Shaw and Gant were interested in exploring positive benefits to communicating online to find decreases in loneliness and depression, and increases in social support and self-esteem. Participants of this study were measured for loneliness, depression, self-esteem, and perceived social support prior to prolonged use in chat environments that were monitored by researchers. After a period of time, participants were retested for each of the variables. Results found positive relationships among the variables. A similar 2003 study focused specifically on loneliness and social uses of the Internet by observing and surveying lonely individuals over time as they used the Internet. This study also found that increased use of the Internet decreased loneliness (Martin & Schumacher, 2003). The present study will focus on loneliness and satisfaction within online support groups by examining the following:

H3: Relational satisfaction will be related to loneliness in a negative manner for patients and caregivers using online CF support sites.
CHAPTER III

METHOD

Procedure

A 54 item questionnaire was created to measure the study variables (Appendix A). Approval for the project was granted from The Human Subject’s Review Committee at The University Akron (Appendix B). The questionnaire was than imported to Checkbox® 4.2, the current supported online survey software used by The University of Akron. The first page visible when participants clicked on the link gave a brief explanation of the project, an informal consent form, and contact information. The survey took about 12 minutes to complete. An invitation and introduction inviting participants to complete the survey explained the purpose of the study. It was posted on several support group sites related to Cystic Fibrosis. A second message with the same link was posted a few weeks after the first one to increase participation. Additionally, in this message, the researcher thanked the original participants for completing the survey, asked for new participation from patients and caregivers who had not yet participated. All participants were informed data results would be posted on the site after completion of the project.

Instrumentation

Relational satisfaction was measured using The Relational Satisfaction Scale (RSS), a 12 item scale developed by Anderson et al. (2001). Examples of items in the scale were: “The group members take time to get to know each other,” “The group
members make me feel a part of the group,” and “My absence would not matter to the group.” Similar to the original scale a 5-point Likert-type scale was used (1 = strongly disagree to 5 = strongly agree). In the present study Cronbach’s alpha was .90 ($M = 27.43$, $SD = 8.77$) which supports the findings for the original scale.

Attitudes toward working in groups was measured using the Attitudes About Groups Scale developed by McCroskey and Richmond (1989). The 7-point bipolar scale consists of five items (good/bad, wrong/right, harmful/beneficial, fair/unfair, wise/foolish, and negative/positive). Participants were asked to describe the way they feel in each statement. The original scale had a coefficient alpha of .95 ($M = 32.20$, $SD = 9.73$), while the current study’s findings was equally reliable with a coefficient alpha of .89 ($M = 13.83$, $SD = 5.94$).

Social support was measured using the Duke-UNC Functional Social Support Questionnaire (FSSQ) developed by Broadhead et al. (1988). The questionnaire used 8 of the original 10 items. The two items dropped (I get…”help when I need transportation” and “help when I’m sick in bed”) were found to be not applicable to an online group setting. Examples of items used included: I get…”help with my outlook about my self,” and “help with motivation to make improvements about my situation.” The scale items utilized a 5-point Likert-type scale (5 = as much as I would like to 1 = much less than I would like). Coefficient alpha for the current study was .89 ($M = 27.43$, $SD = 8.7$).

Loneliness was measured using the revised 20-item UCLA Loneliness Scale developed by Russell, Peplau, and Cutrona (1980). Participants were asked to describe the way they feel about each statement. Examples of items included: “I feel in tune with the people around me,” and “I feel left out.” Items were placed on a Likert-type scale (1 =
never to 5 = always). In the present study the scale has a reliability coefficient alpha of .94 \((M = 41.37, SD = 14.1)\).
CHAPTER IV

RESULTS

Participants, $N = 73$ (7 Men, 64 Women), included 53 caregivers and 20 patients. Age of participants ranged from 21 to 60+ years of age. The mean range was 41-45 year with a $SD = 1.9$. The support sites utilized were Cystic Fibrosis sites on Yahoo Groups, My Space Groups, and a Cystic Fibrosis listserv group. Participants reported logging onto the website from everyday or weekly, to “only when I need help.”

The first hypothesis focused on attitudes toward online support groups and relational satisfaction. A Pearson $r$ correlation analysis resulted in a significant and moderate to strong relationship in a positive manner, $r = .49$, $p < .01$.

The second research hypothesis focused on social support and relational satisfaction, proposing that social support would relate to relational satisfaction in a positive manner for patients and caregivers using online support groups focused on Cystic Fibrosis. As predicted, a Pearson $r$ correlation analysis resulted in a moderate strong relationship of $r = .54$, $p < .01$ in a positive manner.

The final hypothesis (H3) focused on the relationship between loneliness and relational satisfaction. The prediction was that loneliness would be related to relational satisfaction in a negative manner. The data supported the hypothesis, although the
negative relationship was weak. The Pearson $r$ correlation analysis showed a relationship of $r = -.25, p < .01$.

Further analysis of the data showed significant relationships among two variables. For example, social support shared a strong positive relationship with attitudes toward groups. The Pearson $r$ correlation of $r = .67, p < .01$. Another significant but negative relationship was found between social support and loneliness with a Pearson $r$ correlation of $r = -.55, p < .01$.

Four of the participants provided unsolicited feedback through e-mail. From the four messages, all gave positive comments and asked to have the results sent to them directly by providing an e-mail address. Comments included “I am very interested in the results of this survey. While I think that some people may belong to these groups to have their sense of ‘love and belongingness’ validated, many are there (myself included) for more strategic reasons,” and “Thank you for focusing on this, I am interested to hear about the results.”
Communication Researchers continue to look at the benefits and drawbacks of online support groups. The field is still evolving and new methods of communicating digitally are constantly being developed. In the midst of this development, groups of individuals who previously had issues functioning in a social environment are finding a way to connect with one another. Although research is growing, there is still a large body of untapped data that exists when investigating online support groups, “Researchers are seeking new understanding of the relationships between participation in an online community and an individual’s offline life and the dynamics of group interaction online” (Maloney-Krichmar & Preece, 2005, p. 203). The interaction that occurs can be a result of many factors, such as the virtual environment that draws individuals to a particular site, the type of media used, and the design of a particularly useful site. Additionally, the focus can be on the individuals using the site.

The benefits of online support groups can easily be seen by searching any topic related to a social issue to explore the sheer number of currently available sites, the number is usually very large. Individuals have gravitated to the benefits of using online support for many reasons. Convenience is the greatest benefit; however, a number of these individuals have mobilization issues, some have unwillingness to communicate
issues, and some are inflicted with a disease that prevents prolonged exposure to others due to the risk of cross-infection from exposure to others. What has not been examined is the relational satisfaction that participants forced to communicate in an online environment receive from participating in something other than a face-to-face forum.

Schutz’s Interpersonal Needs Theory provides a foundation for understanding the needs that people have to feel included, to establish relationships with others and to feel they are in control of stressors in their lives, such as with Cystic Fibrosis. Participants in the study are developing and maintaining personal ties in an online environment by participating regularly in those important sites.

As the current study demonstrates, relational satisfaction in any group situation and more importantly found in social support groups, may be the ideal individuals coping with Cystic Fibrosis strive for. The idea of satisfaction in an online support group can have more than one definition. For example, the difference between satisfaction with the information received, satisfaction with the way a program is presented and the ease of use, or the perceived satisfaction of relationships made and maintained on the sites are all avenues that can be examined communicatively. This study’s contribution focused on the perceived relational satisfaction among group members for the first time in an online environment. In addition the study investigated variables thought to be related to a model of relational satisfaction online.

The first variable examined the attitudes toward online support groups and relational satisfaction. The study found an encouraging link between them. Previous research indicates that individual perception about participating, either from previous group experiences or from lack of group experience, can greatly influence the perceived
relational satisfaction of the individual with subsequent group interaction (Anderson, et al. 2001). The current study supports the idea that when an individual seeks to satisfy interpersonal needs those needs can be met in an online context. Future researchers will benefit from the understanding that this variable plays an important role in online research of support groups.

The second hypothesis looked at relational satisfaction and social support. The findings support previous research indicating that individuals seeking social support find satisfaction in support situations for a variety of life situations and for coping with perceived life stressors (Albrecht & Adelman, 1987; Cohen & Syme, 1985; Wright, 1999 & 2000). Previous research has also indicated that satisfaction goes up over the longevity and frequency of participation within computer mediated communication (Caplan & Turner, 2007; Wright, 2000). The current research focuses on individuals personally involved with the disease Cystic Fibrosis. Since this disease affects a relatively small number of individuals throughout the world, it is possible that the individuals inflicted with this disease, or caring for a loved one inflicted with this disease, get the majority of their information and support from the CF online sources.

One development from this study was the finding that social support dimensions (informational support, tangible, esteem, emotional, and social network support) are not adequately measured in an online setting. Future researchers may want to address this issue.

The final relationship examined was between loneliness and relational satisfaction. Previous research on loneliness indicates that although it is difficult for individuals to define loneliness, it is not difficult for individuals to report feeling lonely.
From communication competence, to lack of social interactions, or communication apprehension, many indications of causes of loneliness have been studied from a communication perspective (Anderson & Martin, 1995; Rook, 1988). The current study found a strong negative relationship between the variables loneliness and relational satisfaction. Loneliness may be the reason for CF patients or caregivers to seek relationships that provide information or support, or may be a result of the relationships inadequately built in a social setting. This speculation is an avenue for continued investigation.

Study Limitation

Online support groups, as well as computer mediated communication, have grown exponentially over the past few years. As reported by Wright (2000),

The move to the on-line environment of these groups presents new challenges for communication researchers in light of the complexity of social support itself and the added issues inherent in communicating within a computer-mediated environment. (p. 44)

This current study adds to the foundation of recent research focused on communication variables in an online environment. However, a few limitations exist which are explained as follows.

The number of survey participants could be enhanced by persistence of reminder posts and e-mails sent to individuals using online support groups focused on Cystic Fibrosis. In addition to subsequent invitations and reminders to increase sample size, this research was not able to gain approval from the administrators of one of the larger Cystic Fibrosis online support groups. This particular site has a well established group of individuals involved in posting messages and relaying information. In addition, the site
offers advice from experts working in fields related to Cystic Fibrosis. These influences have built the site to be well attended and respected throughout the Cystic Fibrosis community. Gaining access to these message boards or having the ability to exercise freedom of the Internet rights, as well as having the ability to provide links to future research efforts may result in a larger sample population, especially of patients.

Another limitation of the study pertains to the survey instrumentation used. It was important to the researcher to utilize a social support instrument that focused on each aspect of social support model outlined and defined by Cutrona and Suhr in 1992. According to their study

different kinds of social support are most useful in the context of different kinds of stressful life events. More specifically, social support components that promote action are most beneficial following events that can be controlled by the victim, and that components that promote comfort or healing are most beneficial following events that cannot be controlled by the victim. (p. 168)

The questionnaire instrument for the social support aspect of this study (Broadhead et al., 1988) did not serve this function by asking questions only pertaining to four of the five aspect of the social support model. In addition, their survey was specifically written for face-to-face support situations. Questions asking participants to describe how much help they get “when they are sick in bed,” were kept in the survey by the researcher under the pretense that online support may extend instrumentally to offline physical help. However, analysis of the data showed that this is physical assistance between online support members is probably rare.

A newer version of the UCLA Loneliness Scale (version 3) has been created as a result of additional research (Russell, 1996). The use of this new scale should be examined and may gain better results within an online environment.
Another point discussed by researchers focusing on computer mediated communication is the complexity in use and limitation of online survey software. Wright (2000) states: “the use of on-line questionnaires creates problems that are different from traditional face-to-face survey research…the anonymity of the medium raises questions about the integrity of the data” (p. 56). Duplication in responses from a single individual, as well as individuals from outside of the target population participating is a situation that will need to be addressed by future survey software development. However, with a medium as rich in information as the Internet, it is an issue that should not hinder further current focus even with limitations.

Concluding Remarks

The current study provides fodder for future research focused on the rapidly growing study of online support groups. Other groups, similar to Cystic Fibrosis communities, struggle with similar issues such as cross-contamination and population size. These types of Internet groups could easily be the focus of future research in addition to being used for comparative purposes to this study.

This study’s focus was on a unique population of individuals in an online environment examining several variables used frequently in communication research. The results provide a wealth of information to add to the growing number of studies related to computer mediated communication and specifically to online support groups.
Table 1
Correlations between relational satisfaction and attitudes toward groups, social support and loneliness

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Attitude toward Groups</td>
<td>---</td>
<td>.67**</td>
<td>-.49**</td>
<td>.49**</td>
</tr>
<tr>
<td>2. Social Support</td>
<td>.67**</td>
<td>---</td>
<td>-.55**</td>
<td>.54**</td>
</tr>
<tr>
<td>3. Loneliness</td>
<td>-.49**</td>
<td>-.55**</td>
<td>---</td>
<td>-.25*</td>
</tr>
<tr>
<td>4. Relational Satisfaction</td>
<td>.49**</td>
<td>.54**</td>
<td>-.25*</td>
<td>---</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).
REFERENCES


APPENDIX A

HUMAN SUBJECTS APPROVAL

The University of Akron

NOTICE OF APPROVAL

Date: April 22, 2008

To: Jennifer S. Barber
   2241 7th Street SW
   Akron, Ohio 44314

From: Sharon McWhorter, IRB Administrator

Re: IRB Number 20080414
   "Cystic Fibrosis E-Support Group: Perspectives of Patients and Caregivers"

Thank you for submitting your IRB Application for Review of Research Involving Human Subjects for the referenced project. Your application was approved on April 21, 2008. Your protocol represents minimal risk to subjects and matches the following federal category for exemption:

☐ Exemption 1 - Research conducted in established or commonly accepted educational settings, involving normal educational practices.

☒ Exemption 2 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior.

☐ Exemption 3 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior not exempt under category 2, but subjects are elected or appointed public officials or candidates for public office.

☐ Exemption 4 - Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens.

☐ Exemption 5 - Research and demonstration projects conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or benefits.

☐ Exemption 6 - Taste and food quality evaluation and consumer acceptance studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study's design or procedures that increase the risk to subjects or include activities that do not fall within the approved exemption category, please contact me to discuss whether or not a new application must be submitted. Any such changes or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. If the research is being conducted for a master's thesis or doctoral dissertation, the student must file a copy of this letter with the thesis or dissertation.

Cc: Carolyn Anderson - Advisor
Cc: Rosalie Hall - IRB Chair

Office of Research Services and Sponsored Programs
Akron, OH 44325-2102
330-972-7050 • 330-972-6281 Fax

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☑ Approved consent form/s enclosed
APPENDIX B

SURVEY QUESTIONNAIRE

Dear Participant: Graduate student, Jennifer Barber, of the School of Communication at the University of Akron is conducting a research study. The study will focus on online support group and those participating in such groups. Two separate survey’s have been established, one for participants who have Cystic Fibrosis and for participants who care for another individual with Cystic Fibrosis. Clicking on the link below will take you to each subsequent survey. Doing so indicates that you have agreed to participate in the survey. Thank you for volunteering. Anonymity and confidentiality for individuals participating will be kept. Nothing will be done to trace the identity of participants. Please be sure to read each section carefully and answer all questions honestly. There is no right or wrong answers. The answers will automatically be saved upon completion of the survey. Participation in this study is completely voluntary and you can stop at any time. There are no risks associated with participation in the study. It should take about 15 minutes to complete. Upon completion of this study, a copy of the research findings will be available by public posting of the abstract on this website. The Human Subjects Review Board at The University of Akron has approved the study. If you have questions or concerns, contact Sharon Mc Whorter, Associate Director, Office of Research Services, 330-972-7666. Or, you may contact Dr. Carolyn M. Anderson, Professor, School of Communication, at 330-972-7600. Thank you for your participation!

I understand the statement above and consent to taking the survey.

Yes  No

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Are you a patient with Cystic Fibrosis or are you a caregiver to a friend or loved one with Cystic Fibrosis?

Patient

Caregiver

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## Survey

### Indicate how often you feel the way described in each of the following statements. For each statement select the number that best represents your feelings.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel in tune with the people around me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I lack companionship.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is no one I can turn to.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not feel alone.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel part of a group of friends.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Cystic Fibrosis Patients

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<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel left out.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My social relationships are superficial.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No one really knows me well.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel isolated from others.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can find companionship when I want it.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Indicate how often you feel the way described in each of the following statements. For each statement select the number that best represents your feelings.

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<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are people who really understand me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am unhappy being so withdrawn.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People are around me but not with me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There are people I can talk to.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There are people I can turn to.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Indicate how often you feel the way described in each of the following statements. For each statement select the number that best represents your feelings.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lot in common with people around me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am no longer close to anyone.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My interests and ideas are not shared by those around me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am an outgoing person.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There are people I feel close to.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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When participating on the Cystic Fibrosis Online Support Site I feel:

<table>
<thead>
<tr>
<th>Good</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

When participating on the Cystic Fibrosis Online Support Site I feel:

<table>
<thead>
<tr>
<th>Wrong</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

When participating on the Cystic Fibrosis Online Support Site I feel:

<table>
<thead>
<tr>
<th>Harmful</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

When participating on the Cystic Fibrosis Online Support Site I feel:

<table>
<thead>
<tr>
<th>Fair</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>
When participating on the Cystic Fibrosis Online Support Site I feel:

<table>
<thead>
<tr>
<th>Wise</th>
<th>Foolish</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

When participating on the Cystic Fibrosis Online Support Site I feel:

<table>
<thead>
<tr>
<th>Negative</th>
<th>Positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

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In the section below think about interactions you have with members of the Cystic Fibrosis Online support site.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The group members take time to get to know each other.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The group members make me feel a part of the group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I look forward to getting online to participate in the group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not feel part of the group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The members make me feel liked.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My absence would not matter to the group.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For each question think about how the question applies to you and select the number that best represents your feelings.
In the section below think about interactions you have with members of the Cystic Fibrosis Online support site.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

For each question think about how the question applies to you and select the number that best represents your feelings.

1. I can trust group members.

2. I can post anything without worrying about what I say.

3. I prefer not to sign on and participate in the online group.

4. The members made me feel involved in the group.

5. Some of the group members could become my friends.

6. The group atmosphere is comfortable.

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In the section below think about interactions you have with members of the Cystic Fibrosis Online support site.

<table>
<thead>
<tr>
<th>I get...</th>
<th>As Much As I Would Like</th>
<th>Much Less Than I Would Like</th>
</tr>
</thead>
<tbody>
<tr>
<td>love and affection.</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>chances to talk to someone I trust about my personal and family problems.</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>invitations to go out and do things with other people.</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>people who care what happens to me.</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>chances to talk about money matters.</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>useful advice about important things in life.</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Next >>
In the section below think about interactions you have with members of the Cystic Fibrosis Online support site.

<table>
<thead>
<tr>
<th>I get...</th>
<th>As Much As I Would Like</th>
<th>Much Less Than I Would Like</th>
</tr>
</thead>
<tbody>
<tr>
<td>help when I need transportation.</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>help when I'm sick in bed.</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>people who actually understand what I am experiencing.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>good advice about my health and situation.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>help with my outlook about myself.</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>help with motivation to make improvements about my situation.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please tell us about yourself. Are you:

- Male
- Female

Age?

Select:

How often do you log onto the website?

How often do you post on the site?

Next >>

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Thank you for taking the survey.

Next >>