Continuing Camp Oasis:
Adolescent Utilization of Facebook for Social Support

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Abstract

The present study investigates peer relationships in adolescents ages 14-17 with inflammatory bowel disease (IBD) who attend Camp Oasis and utilize Facebook. Social support, social connectedness, Internet socialization, and IBD-specific health-related quality of life measures were taken pre- and post-Camp Oasis, and again after time spent in an IBD-specific Facebook called "Continuing Camp Oasis". Statistical analysis of these measures paired with social network analysis of the Facebook group provided insight regarding if the positive effects that result from peer relationships developed at Camp Oasis are maintained online. Previous work concluded that health-related quality of life improves in adolescents with IBD after attending Camp Oasis, therefore it was expected that the improvement would continue through online interaction for the months following Camp Oasis. Findings from this study will inform the developing body of knowledge regarding social networking in adolescence, the pediatric psychology community, and the Collaborative Chronic Care Network (C3N).

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Chapter 1: Introduction

The purpose of this thesis was to explore the nature of peer relationships between adolescents with inflammatory bowel disease (IBD) through quantitative research methods and social network analysis, and to subsequently further understand the different effects of in-person social support and online social support. The methodology for this particular effort involved surveying adolescents with IBD who attended Camp Oasis, a weeklong pediatric camp experience for youth ages nine through seventeen with this diagnosis.

Of adolescents who are online, 73% use an online social networking site, 31% look online for health information, and 17% look for information online about a stigmatized health topic (Lenhart, Madden, Smith, Purcell, Zickuhr, & Rainie, 2011). Specifically, results from a survey of memebers of IBD-specific Facebook groups and pages, Facebook was reported as the third most accessed source for health information (Marticke, 2010). Given the relative inaccessibility of in-person social support interventions such as camp and the increasingly virtual nature of our society, it is important to investigate the benefits and weaknesses of peer relationships in this chronic illness community that are fostered via social networking sites like Facebook.

Participants (n=21) ages 14 through 17 diagnosed with IBD were administered questionnaires to measure social support, social connectedness, health-related quality of life (HRQoL), and Internet socialization before and after attending camp, and once more after two months of active participation in a Facebook group titled "Continuing Camp Oasis" (CCO). Results suggested

improvement in social connectedness, social support, and overall HRQoL over the three measurement points. Additionally, primary conclusions derived from these results suggest that Facebook is great for breadth of social support, but not necessarily depth and because of this, has the potential to foster a greater sense of social connectedness than in-person environments like Camp Oasis. In terms of HRQoL, correlational analyses suggest that emotional functioning, which can be enhanced by social connectedness and support, likely influences bowel and systemic symptoms in this illness population.

The methodology and findings from this work make a significant contribution to the body of work in the role of online social support in adolescents with chronic illnesses. The research efforts put forth by the principal investigator (PI) are representative of a major culture shift: the health care social media movement. Challenges and limitations include a small sample size, time constraints, and potential recruitment biases, all of which are discussed further in this thesis. Finally, the emerging research questions and implications from this study will serve to inform the field of pediatric psychology and the Collaborative Chronic Care Network (C3N Project).

A Brief Etiology of Inflammatory Bowel Disease and Psychosocial Effects

Inflammatory bowel disease (IBD) includes both Crohn's disease and ulcerative colitis; two chronic intestinal illnesses without known cures. Most individuals with IBD are diagnosed in childhood and adolescence and the majority are located in northern Europe, Scandinavia, New Zealand, and the United States. This autoimmune condition can produce damaging inflammation at

any point along the digestive tract. Illness activity occurs in periods of what are known as "flare-ups" and remission. The duration and frequency of "flare-ups" and remission states vary greatly between individuals, which prove to make the illness difficult to treat. In addition to the unpredictability of a flare-up, symptoms often vary both within and between individuals. Symptoms can include ongoing or recurring diarrhea, pain, poor appetite, and growth retardation. Available treatments include anti-inflammatory medication, immunosuppressive pharmaceuticals, dietary and lifestyle adjustments, surgical interventions, nutritional supplements, bowel rest, holistic remedies, etc. (Nicholas, Otley, Smith, Avolio, Munk, & Griffiths, 2007).

As a result of the nature of the illness, children and adolescents with IBD are at a particularly high risk for negative psychosocial outcomes including but not limited to stress, social strain, altered self-image, and psychiatric maladjustment (Nicholas et al., 2007). These individuals are considered more at risk for depression and anxiety specifically, and have been found to have higher rates of depressive and internalizing disorders when compared with youth with other chronic conditions (Greenley, Hommel, Nebel, Raobin, Li, Simpson, & Mackner, 2010). They are also at an increased risk for psychosocial and social dysfunction compared with healthy peers (Hommel, McGraw, Ammerman, Heubi, Hanse, Dunlap, & Beidel, 2010). The previously mentioned unpredictability of symptoms may cause adolescents to limit their social activity and feel different than their healthy counterparts (Greenley et al., 2010). It is this isolation that can cause impairments in social functioning during adolescence,

which is the time of development in which both identity and social skills are primarily developed.

In addition to impairments in social functioning, individuals with gastrointestinal (GI) complaints have higher levels of anxiety and depression (Hommel et al., 2010). Participants with GI disorders were evaluated on seven factors: general distress, somatization, panic/phobia, paranoia/hostility, irritable depression, sleep disturbances, and psychoticism and it was found that this illness population exhibits high levels of irritable depression and somatization (Kovacs, Seres, Kerekgvarto, & Czobor, 2010). Chronic illness is a stressful event at any stage in life, but becomes a significant risk factor for the development of an anxiety disorder in an adolescent. Pao and Bosk (2011) investigated anxiety in medically ill children and adolescents, and found that anxiety in this population not only affects medical non-adherence and other co-morbidities, but also directly affects symptom management, medical outcomes, and coping abilities. Also, higher rates of anxiety in this population are accounted for by interactions between disease-related and psychosocial factors. Often symptoms can be brought on or intensified when one is experiencing stress and anxiety, therefore there is clearly a connection between disease activity, psychosocial adjustment, and anxiety or depression (Pao & Bosk, 2011).

When dealing with a chronic illness, the individual with the illness is not the only one to experience stress. When there is anxiety in the family setting, it can affect parenting patterns, which in turn may perpetuate maladaptive adolescent behavior. In a study of twenty families who had children with IBD, the

mothers in the IBD group scored very high on parental distress and both parents reported significantly low scores on social support (Engstrom, 1991). In addition, the mental health of the participants in this sample was correlated with the social support they received from their parents. This is another reason why it is important to manage the anxiety that may co-occur with an adolescent who has been diagnosed with Crohn's disease or ulcerative colitis.

Current Interventions and Existing Resources

Cognitive-behavioral therapy (CBT) is currently one of the only evidence-based treatment programs for people with IBD and anxiety or depression. Effective CBT emphasizes that the individual recognizes their cognitively distorted thoughts and helps them to replace those thoughts with more rational ideas. Szigethy et al.'s (2005, 2007) implementation of a CBT intervention with adolescents with IBD and sub-syndromal depression rendered significant improvement in parent- and child-reported Children's Depression Inventory and Perceived Control Scale for Children. More specifically, those that received CBT showed significant improvements in depressive symptoms, global adjustment, and physical functioning from the parent and child perspective. Research assessing the effectiveness of CBT has only been done on a very small scale, emphasizing the impracticality of these methods alone.

According to Barrera and Prelow (2000), there are three types of social support interventions for children and adolescents: mentoring, support groups, and changing settings, all of which have been shown to be quite effective. Mentoring occurs when a more experienced person transmits knowledge to a less

experienced person, and does not necessarily require an emotional connection between the two persons. These interventions usually include one key person; generally the more experienced person who can sometimes be a professional, but does not have to be (Barrera & Prelow, 2000). Naturally occurring mentoring relationships in particular can be very significant and powerfully effective for all of those involved. Natural mentors are often older members of the community that do not structure the youth's life, but instead provide guidance and opportunities to learn (Lentz & Allen, 2007).

In taking a closer look at the mechanisms of a mentoring relationship, researchers have defined some key dimensions that ought to exist in a successful mentoring relationship: trust, mutuality, empathy, authenticity, engagement, and empowerment. Mentoring relationships including all of those factors were found to be better predictors of positive outcomes than their more structured counterparts (Spencer, 2007). Spencer (2007) also notes adolescence as "a particularly critical time for youth to have a close connection with an adult" (110). There has been a wide range of work documenting the effectiveness of mentoring in diverse settings; however, illness-specific mentoring programs have not been sufficiently evaluated.

Cross-age peer mentoring signifies a developmental relationship between a younger and an older peer within the same generation in which the mentor's focus is to facilitate youth development. The most well known example of cross-age peer mentoring is the Big Brothers Big Sisters (BBBS) program. The theory behind cross-age peer mentoring borrows from Vygotsky, Piaget, and Sullivan; all

of whose theories of development focus on the interaction between social context and cognitive development, more specifically, how social perspective-taking capabilities may shape and be shaped by social interaction (Karcher, 2005). Karcher (2005) suggests that an effective cross-age peer mentoring program must "emphasize the importance of an empathic, supportive relationship over an emphasis on task completion, train the adolescent mentors to use effective discipline and encouragement practices that minimize the likelihood that mentors with use coercive, manipulating behaviors to get mentees to behave or participate, and actively monitor and publicly acknowledge the mentors' use of assertive and empathic communication" (279). He cites Bandura's ideas on how to properly train and motivate adolescent mentors to be able to cognitively comprehend their mentees varied reactions to their involvement as well, which highlight the central role of individuals' prior experience and capacity to relate to others as being the key characteristics of a strong mentor. This focus of socialization is particularly relevant to adolescent development, and as previous research is shown, this may justify why mentoring programs and social support interventions in general are so effective in this stage of development, especially in a population that can tend to feel very isolated and alone.

Group-based interventions that utilize social support as the main mechanism for dealing with the psychosocial effects of having various chronic illnesses have been proven to correlate with increases in health-related quality of life and other positive health outcomes. In a review on group interventions for pediatric chronic conditions, the following categories emerged: (1) emotional

support groups, (2) psychoeducational groups, (3) adaptation/skill development groups, (4) symptom reduction groups, and (5) summer camps (Plante, Lobato, & Engel, 2001). Interestingly, this systematic evaluation of group interventions showed that groups did not always result in their intended outcomes. For example, "emotional support groups aim to increase perceived social support and decrease isolation. However, treatment adherence or symptom control was a measured outcome in some studies reviewed" (p. 443).

Another example of this was a group intervention designed to improve school functioning in adolescents with co-occurring chronic pain and depressive symptoms found was that depression accounted for more variance in functional disabilities resulting from missed school than pain severity (Logan & Simons, 2010). Most chronic illnesses cause youth to miss school due to treatment, procedures, pain, and hospital stays; and IBD is no different. School attendance is extremely important in the developmental stage of adolescence; it allows for the adolescent to properly socialize with their peers, conceptualize goals in terms of achievement, increases intrinsic motivation to do well, and increases attributions such as self-efficacy and self-confidence. This particular intervention utilized both CBT and social learning theories in an effort to increase peer support, decrease feelings of isolation, increase problem solving, and increase self-efficacy in the face of pain. The intervention also taught the participants acceptance-based strategies to aid in their ability to lead a more "normal life." (Logan & Simons, 2010). This research highlights the value of the group setting when looking at depression and anxiety in people with chronic illnesses, specifically IBD. As most

previous research has done, Logan and Simons (2010) iterated that social support is an integral component of adjustment in adolescence regardless of whether or not that individual is dealing with a chronic illness. In summary, these examples further prove how social support for youth with chronic illnesses can have wide-reaching positive effects on health behaviors, somatization, psychopathologies and ultimately their health-related quality of life.

The third social support intervention for adolescents is changing settings, such as leaving home for an extended period of a time to spend a summer at camp, for example. A study on a summer camp for inner-city youth evaluated the construct of hope as a measure of effectiveness. The camp was geared at developing dance skills and psychosocial competence, and results displayed a significant positive change in hope between the pre and post evaluations of the campers (Kirschman, Roberts, Shadlow, & Pelley, 2010). Youth with chronic illnesses are considered at-risk youth given the previously discussed research, and thus have the potential to similarly benefit from camping experiences, and this has been documented across various chronic conditions.

Shepanski et al.'s (2005) work on health-related quality of life in children and adolescents with IBD after attending Camp Oasis, a weeklong regional camp held across the country sponsored by the Crohn's and Colitis Foundation of America (CCFA), indicated that after attending camp, attendees, all of whom had been diagnosed with IBD, showed improvement in bowel symptoms, social functioning scores, and treatment intervention scores. Similar results have occurred across studies on healthy adolescents who attend summer camping

experiences. In a recent effort focused on measuring social competence in adolescents, researchers gave tasks to small groups of adolescents who had attended a summer camp together. Behavior scales were developed to measure peer competence in terms of enjoyment, involvement, leadership, self-confidence, and overall social competence in the task. Results emphasized the importance of group functioning in peer competence during adolescence (Englund, Levy, Hyson, & Srouf, 2000). Camp is not accessible to all adolescents as it is a luxury expense for most families, especially families of children or adolescents with a chronic illness such as IBD that requires expensive treatments and frequent clinic visits. The Crohn's and Colitis Foundation of America (CCFA) offers need-based scholarship opportunities, however they are not available for all campers due to limited resources.

Adherence to Treatment, Social Support and Quality of Life

Social support has been shown to have a main effect on coping mechanisms, health outcomes, adherence behaviors, and other similar constructs paramount to the psychosocial adjustment and overall well-being of a child or adolescent with IBD. A recent study showed that prosocial support may buffer children with IBD from experiencing negative effects of peer victimization on treatment adherence (Janicke, Gray, Kahhan, Follansbee Junger, Marciel, Storch, & Jolley, 2009). In other words, if a child with IBD has a strong social support system surrounding them, the peer victimization that can result from some of the treatments for or symptoms of IBD (i.e. steroid usage, nasal-gastrointestinal tube feedings, stunted growth, and frequent bathroom usage) will have far less of an

effect on that child. This study cited poor treatment adherence as one of the effects of peer victimization, and through child, parent, and physician reports on treatment adherence, confirmed that in fact prosocial support can have a positive impact on treatment adherence (Janicke et al., 2009). In an effort to evaluate the potential connection between treatment adherence and quality of life in a sample of youth with IBD, most adolescents reported accidental nonadherence while a smaller group reported volitional nonadherence. Perhaps more importantly, volitional nonadherence was associated with greater disease activity and poor psychosocial quality of life while accidental nonadherence was unrelated to these constructs (Schurman, Cushing, Carpenter, & Christenson, 2009). Nicholas et al. (2007) also aimed to understand their quality of life and in doing so found that they reported that support from family members and friends contribute to effective coping. Also, Engstrom (1991) correlated the mental health of children with IBD with their parents' social support levels. However, the results from these studies describe the effects of prosocial support from any friends or family members, not solely peers with IBD.

A common thread among social support in people with IBD, and most serious chronic illnesses for that matter, is the desire to belong to a community where their symptoms and disease-related issues are commonplace, and thus free from stigmatization associated with digestive diseases (Vassilev, Rogers, Sanders, Kennedy, Blickem, Protheroe, Bower, Kirk, Chew-Graham, & Morris, 2010). Results from an investigation regarding social support in relation to psychosocial distress and disease activity in people with IBD indicated that improving social

support and access to it elicits favorable impacts on psychological distress and health outcomes. However, the positive effects associated with social support only occurred if the participants were satisfied with the level of social support they were receiving. Children and adolescents with IBD reported being satisfied with social support and smaller network sizes, and subsequently the relationship between psychological distress and perceived stress depend on this satisfaction (Sewitch, Abrahamowicz, Bitton, Daly, Wild, Cohen, Katz, Szego, & Dobkin, 2001).

On the whole, research has yet to effectively determine causation patterns between social support, adherence to treatment, quality of life, disease activity, and developmental psychopathology. Given the consensus on the correlational data summarized above, it can be postulated that social support has a primary effect on the interactions between these factors. In that vein, the present study will compare social support obtained at Camp Oasis with social support obtained via membership of a Facebook group in relation to quality of life in order to make recommendations for increasing the accessibility of social support and explore the effectiveness of online social support as a viable intervention for young people with IBD.

The Endangerment of Support Groups for Pediatric Patients with IBD

In an effort to conduct an ethnographic analysis of the culture of an in-person pediatric support group through participant observation and interviewing, it was found that locally, these groups were no longer in existence, barely have meetings, or have no regular attendees. The lack of formal in-person support

groups for this population is concerning, especially given the previous research that has shown time and again how beneficial these interventions can be for youth with IBD. Therefore, a study was formulated around the concept that these groups do not function regularly, thus rendering them an almost ineffective mechanism for social support for current children and adolescents with IBD. Young people with IBD and mental health clinicians familiar with this illness population were interviewed regarding their experience of this phenomenon. Results indicated shared experience, information-seeking, and resourcefulness as driving forces behind support-seeking. In response to the hypothesis of the impact of the Internet, participants cited accessibility and social competence as potential factors related to virtual social support. Finally, when asked about the nature of in-person social support as it currently stands, participants commented on the structure of interventions and stigmatization as being reasons why they are not utilized as often as research suggests they should (Plevinsky, 2011).

Many factors were considered that may have contributed to the decline of support groups including the busy lives of youth and their families and lack of clinical resources, but the primary finding was that the Internet has had a monumental impact on the way young people with chronic illnesses, including IBD, seek social support and health information. In support of this, adolescents self-report the Internet as their primary information source and thus has found an important place among adolescents' repertoire of health information (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005) and networked publics such as Facebook, MySpace, and other online communities have become a major part of adolescent

socialization (Boyd, 2008). In adolescents with diabetes, Facebook provides a forum for reporting personal experiences, asking questions, and receiving direct feedback, which are basically the main components of a support group (Greene et al., 2011). A recent survey of people with IBD by Kaminsky and Marticke (2011) showed that 87% of respondents use Facebook to connect to others with IBD and that they are willing to share symptoms, treatment options, physician recommendations, and social situation advice online.

A recent report curated by Susannah Fox of the Pew Internet & American Life Project (2011) explored how adults are using the Internet for health information with a specific focus on the social nature of the medium. Below is the summary of the findings from the adults surveyed who self-identified as both Internet users and users of social networking sites (Fox, 2011):

- 23% of social network site users, or 11% of adults, have followed their friends' personal health experiences of updates on the site.

- 17% of social network site users, or 8% of adults, have used social networking sites to remember or memorialize other people who suffered from a certain health condition.

- 15% of social network site users, or 7% of adults, have gotten any health information on the sites.

- 14% of social network site users, or 5% of adults, have posted comments, queries, or information about health or medical matters.

- 9% of social network site users, or 4% of adults, have started or joined a health-related group on a social networking site.

Keeping in mind that these results are based on the adult population speaks volumes for adolescents who utilize social networking sites more readily and frequently than their adult counterparts. Based on this research and the trend toward an increasingly socially virtual society, it is important to consider the impact that the Internet has had on both support groups and adolescent health in general.

Social Networking and Internet Use in Adolescence

Researchers at the Pew Internet & American Life Project who make it a point to consider how the Internet has made an impact on adolescent development and health care. While some of the previously mentioned studies have cited limitations such as too small of a sample size or lack of longitudinal data, innovative researchers are working to develop ways to consider the specific effects of an our virtual society that has been fueled by the development of Facebook and other various social networking websites. Boyd (2008) lends her expertise to the issue of why teens love social networking:

> "The rapid adoption of social network sites by teenagers in the United States and in many other countries around the world raises some important questions. Why do teenagers flock to these sites? What are they expressing on them? How do these sites fit into their lives? What are they learning from their participation? Are these online activities like face-to-face friendships or are they different, or complementary? The goal of this chapter is to address these questions and explore their implications for youth identities. While particular systems may come and go, how youth engage through social network sites today provides long-lasting insights into identity formation, status negotiation, and peer-to-peer sociality"
> (p. 119).

The Internet's influence on social connections and relationships within our modern society has been monumental, and the impact on healthcare and medical

informatics is becoming increasingly controversial in terms of how people ought to obtain reliable information and still maintain their privacy in the process. The increasing rate of adolescent participation on these sites holds serious implications for the population with IBD as they transition from their parents' care to being responsible for taking their medications and watching their diets, for example.

Greenfield and Yan (2006) identified three major themes that ought to be considered in this relatively new context of adolescent development: (1) communication on the Internet, (2) cognitive development, academic achievement, and the Internet, and (3) adolescents in a globalized Internet world. The specific developmental functions include developing a cognitive understanding of the Internet and social development, particularly identity, self-worth, sexuality, health behaviors, and leadership. In order to effectively determine how the Internet has impacted these paradigms, it must be regarded as a new social environment in which adolescents explore issues that have historically plagued adolescent development throughout history.

Similar to the idea that for children, play is a safe way to experiment with social situations and one's identity, personal homepages provide adolescents with a space where they can do the same thing. Results from two studies exploring the role of personal homepages in relation to mastery and identity formation indicate that young people use the online space to express and explore their forming identities (Schmitt, Dayanim, & Matthias, 2008).

In addition to exploring their identities, adolescents also use the Internet to seek information regarding their health. Participants in a survey of youth Internet

use reported the top three subjects of their health-related online information searches were specific diseases, sexual health, and weight loss. On the whole, adolescents view the Internet as a good source for health information and for both "socio-affective regulation" and "goods-and-information acquisition" (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005). As a result, the nature of information seeking online for health topics is becoming more social giving way to the concept of networked health: the idea that people can get health information from one another via their social network (Fox, 2011).

This trend is especially apparent in adolescents with IBD who may feel isolated or even stigmatized due to the unpleasant symptoms that accompany a flare-up. Often, a solution to this is to normalize the illness experience through social support.

> "The role of others in defining normalcy and deviance has been latent and the main focus in the literature has been on stigma as a personal experience. However, stigma is necessarily construed and experienced in relations with others, and therefore structural social position and social relational elements of stigma are likely to have an impact on how it co-shapes the everyday practices that are relevant for illness management as well as one's sense of well-being" (Vassilev et al., 2010, p. 6).

Krause (2003) defined normalization as a central component of transformations of social representations of disease, in other words, an attitudinal change characterized by higher tolerance, acceptance of social support, and recognition of the process of accepting having a chronic illness such as IBD. Krause (2003) argued that social definitions of illness are becoming increasingly important and emphasized the potential for social support to promote positive health outcomes. The self-help intervention program implemented in this study aided in coping by

decreasing feelings of isolation and shame; increasing emotional support, practical help, and general knowledge; developing a strong group identity, maintaining a positive emotional environment, giving and receiving mutual social support, and validating the group within the individual's social context. Krause's (2003) clear definition of self-help groups bares an uncanny resemblance to the function of IBD-related Facebook groups: "Self-help groups are voluntary, small groups, structured for the mutual help and the attainment of a specific purpose. They are generally formed by peers that meet to help each other: for addressing a common need; coping with a common handicap, or with a problem that alters the normal course of life; or for achieving a social change regarding the shared problem" (p. 601).

There are obvious concerns associated with online communities on a policy level, especially when adolescents report being unable to identify credible sources of information (Gray et al., 2005) and are already developmentally prone to risk behavior. An exhaustive review of online social networks for people with diabetes concluded that the quality and safety of these networks is variable (Weitzman, Cole, Kaci, & Mandl, 2011). With a majority of these communities existing as groups and pages on Facebook, it is important to conduct qualitative evaluations of the type of things being discussed and the nature of the information being shared on this platform. In the diabetes communities, it was found that people tend to share personal clinical information and are met with emotional support and disease-specific guidance and feedback (Greene, Choudhry, Kilabuk, & Shrank, 2011). The following study by Plevinsky, Goldenhar, and Jackson

(2010) explores the activity of Facebook communities specific to those with IBD and found that similar discussions were being had in this illness population as well.

Facebook as a Tool for Social Support in Young Patients with IBD

An original study was developed to test the prediction that most people already active on IBD-specific Facebook groups and pages will seek after higher levels of social interaction in response to discussions regarding diet and peer acceptance as opposed to more private or stigmatized matters such as drug and treatment options or side effects. These topics were chosen based on a compilation of the information from Nicholas et al.'s (2007) previously mentioned work as well as measurements of the public activities of people with IBD on Facebook (Gloor, Grippa, Bogert, Colletti, Dellal, Margolis, & Seid, 2010). Findings indicated that many separate and small communities do not interact with one another; however, they tend to discuss the same things. In considering the following study, it is important to remember the over-arching theme that one cohesive network would be beneficial to the illness community because members with a longer trajectory of illness will tend to teach their competencies to members with more recent diagnoses (Krause, 2003).

Participants were prompted to respond to prototype posts made by two established Facebook users with IBD, one female and one male. The posts were developed so that there were four for each category (drug/treatment concerns, diet, and peer acceptance), two of which were developed and posted by the female and two of which were developed and posted by the male so as to elicit equal

response from both sexes. In looking at topic choices as well as which Facebook groups to target, Gloor et al.'s (2010) analysis of Facebook activity on IBD sites was consulted and groups and pages were chosen. Both the female and male users posted the prototype comments on the walls of these sites and recorded responses. The posts were transcribed for further and more detailed review. It was found that peer acceptance posts elicited the most responses and the longest responses on average. The diet posts elicited the second most responses and the second longest responses by a small margin, but resulted in the most friend requests, and "likes." Drug/treatment concerns were the least discussed and engaging posts altogether suggesting that peer acceptance and diet take precedence over drug/treatment concerns in the search for online information and social support via IBD-specific Facebook groups and pages (Plevinsky, Goldenhar, & Jackson, 2010).

The present study focuses on exploring the effectiveness of online social support through a brief trial following 21 adolescents with IBD as they attend a session at Camp Oasis and then as they socialize in a Facebook group. In addition to brief ethnographies describing Camp Oasis and illness-specific Facebook groups, the following primary research questions were developed with regards to personal experiences of the PI and deficits in existing literature on this topic: 1a) Does attending Camp Oasis improve adolescents' HRQoL, social support, and social connectedness? and 2a) Does participating in a Facebook group diminish, maintain, or intensify the effects the Camp Oasis expereicne may have on an adolescent's HRQoL, social support, and social connectedness? It was hypothesized that HRQoL, social support, and social connectedness would

improve in this population of adolescents after Camp Oasis, and would continue to improve after time spent in a Facebook group with their fellow campers. Secondarily, 1b) Which habits and metrics characterize these adolescents' utilization of social networking websites? and 2b) What implications for practice emerge from exploratory correlational analyses between results from the questionnaires and social network analyses? Since these questions were more exploratory in nature, the PI did not develop specific hypotheses. However, given both the PI's personal and research experience, it was expected that positive correlations between social support and HRQoL would emerge, as well as correlations between social support and social connectedness measures.

Average scores from the multiple measures collected pre Camp Oasis, post Camp Oasis, and post Continuing Camp Oasis will be reported for analysis and activity within the Facebook group will be reported via social network analysis so as to better understand the nature of communications in this particular illness population. Discussion and conclusions will further address risks, recommendations, and how physicians, researchers, patients, and their families are currently working together to innovate pediatric health care for people with IBD as a part of the Collaborative Chronic Care Network (C3N Project) and ImproveCareNow. Findings from this particular work combined with the previously discussed research on the challenges of having a chronic illness as an adolescent, the lack of accessibility to in-person resources, the importance of social support, and the emergence of the Internet as a prominent tool for health

information seeking in young people ought to influence the field to consider the implications of social support in the context of virtual communities.

Chapter 2: Camp Oasis

The American camping experience is a unique culture in itself. Each summer, thousands of children and teens are dispersed across the country at various campsites for the duration of the summer. These camps employ young adults as counselors and hold the promise of socialization, independence, growth, and fun. The American Camping Association formally recognizes that camping has an important impact on child development through "building confidence, self-esteem, teamwork, and fostering appreciation of the environment. Historical consensus exists within social work, the field of mental health, and the general society that camping promotes children's and youths' psychosocial development" (Farber & Sabatino, 2007, p. 387). Research has been conducted on the effectiveness of camping experiences for grieving children (Farber & Sabatino, 2007), talented adolescents (Little, Kearney, & Britner, 2010), inner-city youth (Kirschman et al., 2010), and children with chronic illnesses such as diabetes, asthma, and cancer (Winfree, Williams, & Powell, 2002). A review article on group interventions for pediatric chronic conditions sited summer camps as a separate category and determined that adaptation to illness was, in general, the primary target of the majority of the camp programs, with just a few emphasizing symptom reduction. Overall, pre-post evaluations of these experiences found increased illness knowledge and improvements in self-esteem, anxiety, attitudes

toward the illness, and management of the illness (Plante, Lobato, & Engel, 2001).

The Camp Oasis program began in 2000 under the direction of the Crohn's and Colitis Foundation of America (CCFA), the largest non-profit benefiting both clinical research and support programming for those young and old who have been affected by inflammatory bowel disease (IBD). In its earliest beginnings, the regional camps were each run by individual chapters of the CCFA and had their own unique name, however, they are now all called Camp Oasis and have standardized programming which is subject to vary by site. The present study's site is run by the Philadelphia/Delaware Valley Chapter and is located at Camp Nock-a-Mixon in Kintnersville, PA. Camp Oasis is a co-ed residential camp program with a mission to enrich the lives of children with Crohn's disease and ulcerative colitis by providing a safe and supportive camp community. The program website boasts opportunities for campers to see that they are not alone, create friendships with others who truly understand them, listen to and share their stories with IBD, and gain confidence all with the support of a highly qualified medical staff and traditional camp activities. At Camp Oasis, no camper is turned away based on the complexity of his or her treatment regiment or dietary restrictions. The only health-related requirement is that they be well enough to participate in camp activities.

Traditional camp activities can include both creative and physical programming such as arts & crafts, dance, music, cooking, swimming, sports, boating, etc. There is something for everyone at camp, but not many children with

chronic illnesses are well enough to attend the usual four to eight week sessions. This is why so many camps for youth with chronic illness exist: parents can feel secure knowing that their child will be in the hands of great medical care, and Camp Oasis only lasts a total of six days. Cabins are separated by gender and grade in school, and each cabin is staffed with two to four volunteer counselors, most of whom either have IBD themselves, or are close to someone with the diagnosis. The relationship between campers and counselors is unique and resembles a mentoring relationship that through social media and new technologies has the potential to perpetuate throughout the year. These mentoring relationships are particularly valuable between campers and counselors who have IBD because of the shared experience of the chronic illness. Staff is thoroughly trained to supervise their campers. They receive a quick information session on IBD and are prepared to deal with common issues specific to both IBD and typical developmental concerns such as isolation, homesickness, and misbehavior through role-playing and scenario development during orientation, which takes place the day before the campers arrive.

Arrival

Most campers will arrive by buses from the local chapters, and some campers' parents will bring them to camp. The arrival process is rather intriguing because of the nature of the check-in process as well as the obvious social dynamics between both new and returning campers and staff. In 2000, campers from five distinct chapters of the CCFA attended one camp, but now due the overwhelming demand plus the limited capacity and staffing available after the

regular summer session, Camp Nock-a-Mixon now only accepts campers from the New Jersey and Philadelphia/Delaware Valley chapters of the CCFA. Each bus is scheduled to arrive in the early afternoon and parents drop their campers off periodically throughout the morning.

For those campers who take the bus, their parents check them in at the bus stop, which is usually a relatively central meeting point for that particular region. At each bus stop, there are nurses taking temperatures and checking for head lice, both standard procedures when sending a child off to camp. This is especially important for children with Crohn's disease because of their already compromised immune systems. The campers receive luggage tags labeled with their bunk number and how they arrived at camp so the Nock-a-Mixon staff can organize the cumbersome duffle bags and deliver them to the proper cabins with minimal confusion. The most tedious but also the most important part of the check-in process is of course dealing with each child's medication. In addition to extensive paperwork regarding both physical and mental health, parents are asked to prepare a week's worth of their child's medication in small plastic bags labeled for each day and each meal. Since treatment for Crohn's disease is very individual and is not always in the form of a capsule, the nurses are prepared to label larger items such as enemas, nutritional supplements, pre-loaded injection pens, subcutaneous injection supplies, nasal-gastrointestinal tube feeding paraphernalia, food items, and so on, most of which require refrigeration. A similar check-in process occurs at Camp Oasis with those parents who have chosen to transport their children directly to the campsite.

Once the check-in process is complete, campers are given nametags and are instructed to gather in the outdoor areas away from the cabins. Counselors and staff are prepared to find their campers for the week, play games and icebreakers with the group, and also to notice if any new campers seem uneasy or isolated. Returning campers often keep in touch during the year via Facebook, texting, and other means so they are excited to see one another and especially in the adolescent age groups, cliques begin to form segregating them from those coming to camp for the first time. Returning campers also recognize returning counselors and staff thus forming even more seemingly cliquey relationships. This is part of the reason why we try and the use the afternoon of the first day to play all-camp games and icebreakers to acquaint new and returning campers and reduce the anxiety of the camp environment for those who've never been to camp before.

Mealtimes

At any camp, mealtimes are an experience campers and staff use to bond, talk about the day, and sometimes show cabin spirit. At Camp Oasis, all of these things happen, but there is also a particular order to the progression of dining at breakfast, lunch, and dinner. Each cabin files into the dining hall at the start of each meal and sits at a table labeled with their cabin's number with the exact number of folding chair situated around it to accommodate that cabin's campers and counselors. In the morning, the tables are stocked with water, orange juice, milk, and Lactaid for those campers who are lactose intolerant. Counselors in the younger cabins will pour drinks for their campers upon arriving at the table while older campers will do it themselves, but there are still spills regardless.

As the drinks are being poured, the medical staff arrives with large plastic bins full of the medication for each child that was turned in upon arrival. The nurses situate themselves at the end of each table and provide the counselors (who sit at the head of their cabin's table) with the labeled plastic bags and the counselors distribute them to the campers. Once the entire table has taken their medication, the Camp Nock-a-Mixon staff calls that cabin up to the food line to get their meal cafeteria style. This is just one of the ways that the Camp Oasis experience ensures and promotes adherence to medication. For those medications that are not easily administered in the dining hall, counselors must escort the camper(s) from their cabin to the infirmary at the time of day prescribed.

After all the campers have gotten their meals, they are offered an opportunity to get back in line for a second helping. While at other camps, children might jump at this opportunity. But children with Crohn's disease tend to have extremely suppressed appetites and some of them eat very little because they are aware of how painful digestion can be. However, there are some children on steroid treatment, so those campers on high doses of steroids like prednisone tend to have ravenous appetites and will probably take advantage of the opportunity to satiate their hunger. Camp Nock-a-Mixon, not the CCFA, provides the dining options at Camp Oasis. Therefore, foods served are often more kid-friendly than IBD-friendly. Returning campers privy to this knowledge have their parents send tolerable foods to be kept in the kitchen for them to have access to if the meal is not conducive to their diet.

Daytime Activities

The daily schedule (Appendix A) at Camp Oasis is made up of two hour-long periods between breakfast and lunch, a rest hour after lunch, and three hour-long periods between lunch and shower hour, followed by dinner, which is followed by evening activities. The schedule of a particular cabin varies throughout the week so that they do not have the same activity too many times during camp. However, if a particular cabin all agrees that they prefer for example, arts and crafts over basketball, the schedule can be flexible. The staff at Camp Oasis understands that the campers only spend a short week at camp, and want each camper to be able to enjoy his or herself as much as possible. As mentioned before, these activities range from athletics to creative endeavors so that every camper has the opportunity to excel at a particular activity.

Evening Activities

Evening activities are structured events planned for the campers after dinner until it's time to go back to the cabins and prepare for bed time or "lights out." The evening activities are clearly the most exciting part of the week for the campers because they are mainly socially driven and tend to not be too structured like the daytime activities. Additionally, evening activities are camp-wide so that campers who may not have had daytime activities with one another that day can spend time together at night. There are traditional activities that are conducted each year, with a few variations, but they almost always involve campers bringing costumes to camp. A flyer is sent out before camp so the campers have time to prepare their outfits for evening activities (Appendix A).

The first night of camp, after everyone has settled in his or her cabin, the intercom system calls everyone to the pool area for a luau. At the luau, campers can swim at night, enjoy carnival games, or just hang out around the pool in hula skirts. This activity is fairly unstructured because most of the campers are tired from travelling to camp earlier that morning, and they prefer to have a relaxing evening of lounging and swimming. The second night is the scavenger hunt, which is a competitive event with each cabin being it's own team. The staff creates a series of items to find and tasks to complete in different orders for each cabin, and the first cabin to complete the scavenger hunt wins the competition. The items are things that can be found around camp or that a camper typically brings to camp like a green sock, bottle of nail polish, or a baseball cap with a sports team logo. Once the cabin has gathered these items, they are given a clue to a specific place in camp where counselors are waiting for them and have them perform a certain task. These tasks can include spelling a word on the ground with their bodies or acting out the complete story of Cinderella in 30 seconds or less. The entire activity lasts approximately 60-90 minutes, and once the winner reaches their last checkpoint, the activity is over and all of camp is called back to the center of the campground to announce the winning cabin. Winning the scavenger hunt is not only a source of pride for the particular cabin, but they also get a prize. This year, the prize was having two of the staffers deliver evening snack to their cabin and serenade the cabin before "lights out."

The activity held on the third night of the week is perhaps the most anticipated night of the year for some campers: the dance. The dance is held in a

large recreation hall, and the camp hires a professional DJ for entertainment. The campers get very excited for the dance during the day that it's being held. Some campers even devote their afternoons to both finding dates for the dance and primping. However, the importance of the dance extends beyond the fact that it's fun. Campers look forward to this activity because as discussed, having IBD can inhibit normal socialization for adolescents, which includes attending school dances. At Camp Oasis, adolescents with IBD have the opportunity to have a date and go to a dance with their friends free from the fear of needing to use the restroom too much and the self-consciousness that accompanies this diagnosis during this particular period of development. The staff tends to be excessively concerned about romantic or sexual activity at the dance so they attempt to supervise campers very closely, but on the whole, the campers are just enjoying themselves and having innocent fun with their friends.

The fourth night is another low-key evening because of the previous two high-energy evening activities. Weather pending, the staff organizes to have a large projection screen situated on the campground so that the camp can gather to watch a movie under the stars. The movie chosen is rated PG so that it is appropriate for all of the ages that attend Camp Oasis. Campers and counselors wear sweatshirts and some even bring their sleeping bags, blankets, and pillows to lie on so that they are comfortable during the movie. Snacks like soft pretzels and snow cones are distributed throughout the movie and once the movie ends, everyone returns to their respective cabins for "lights out."

The fifth and final night of Camp Oasis culminates with an award ceremony in which staff and counselors are recognized for their hard work and dedication to the program and to the campers. Most of the ceremony is meant to be entertaining for the campers, so often counselors are recognized for things like "best hair," or "best breakout performance by a female counselor" in the style of the MTV Movie Awards. After the awards are all given out, the staff presents the campers with a short video of all of the photos they've taken that week set to music. Campers cheer when they see their own faces or faces of friends appear in the photos, and it seems like a great conclusion to the week allowing everyone to reflect on their experience at Camp Oasis. At this point, campers return to their cabins for a very flexible "lights out" time and try and make the most out of their last night with their bunkmates and counselors.

Departure

The last day of camp, for most campers is the saddest day of the year. It's the day where they have to go back home to their families and friends, most of who probably do not have Crohn's disease or ulcerative colitis. The campers pack their things the afternoon before departure so that they can have their luggage sorted by the camp staff and loaded onto the proper buses or piled together to be picked up by that child's parent(s). The campers wake up earlier than on a normal camp day so they can make sure they leave their cabins clean and have plenty of time to say goodbye to all of their friends old and new. They engage in a tradition of signing each other's camp t-shirts with permanent marker. Almost all of the campers are either wearing their Camp Oasis shirt or carrying it around for other

campers, counselors, and staff to sign with their name and a short message along the lines of, "I'll miss you!," "Stay in touch!," or "See you next year!"

At around 8 or 9 AM once all of the luggage has been sorted, the campers, counselors, and staff gather in the dining hall for one last breakfast together. The scene is rather chaotic, perhaps even more so than at arrival. Campers are racing across the dining room taking photos with one another and continuing to sign each other's shirts. Some are exchanging phone numbers and email addresses while others are locked in embraces with tears streaming down their faces. The scene is simultaneously heartbreaking and heartwarming. On one hand, it is wonderful that the campers have had such a meaningful experience over the past week and have created bonds with others with IBD that are likely to last a lifetime. On the other hand, it is important to remember the home and school environments the campers return to where they might not be another person with Crohn's disease or ulcerative colitis that they can talk to at any moment.

Camp Oasis truly is a magical place, just as any camp dedicated to serving children with a particular chronic illness can be for a child or adolescent experiencing feelings of isolation as a result of their diagnosis or symptoms. Thus, the importance of having a peer group with shared experiences for a young person with inflammatory bowel disease is particularly important at the adolescent stage of development. The depth of the relationships developed over this week is more than just peer acceptance as evidenced by the emotional distress that occurs on the last morning of camp. Hanna's (1998) research on peer acceptance and friendship in adolescents who attended a weeklong camp experience indicated a distinction

between the two that defines friendship as a more complex construct, which incorporates some elements of peer acceptance such as likability, but also involves intimacy and emotional support (p. 311).

Unfortunately, there are clearly many limitations to pediatric camping as an adequate intervention for adolescents with IBD such as limited capacity, lack of availability, inconvenient locations, illness severity, etc. This is why regularly meeting regional support groups all year long provide more opportunities to access social support. A self-help group intervention evaluated by Krause (2003) showed that the group helped them to transform their own social representations of IBD, which led to normalization and acceptance of the illness, both of which characterize attitudinal adjustment that better allow coping, similar to the positive affects associated with attending Camp Oasis. In alignment with these findings, children and adolescents with IBD reported being satisfied with social support and smaller network sizes, and subsequently the relationship between psychological distress and perceived stress depend on this satisfaction (Sewitch et al., 2001). However, these groups are either no longer in existence, barely have meetings, or have no regular attendees, and as it turns out, young people are going online instead.

Chapter 3: Facebook

"Patients with inflammatory bowel disease (IBD) are turning to the Internet to learn about their disease and communicate with others in similar situations. They tend to be younger, sicker, and more educated than patients who do not use the Internet" (Fortinsky, Fournier, & Benchimol, 2011). There are a

few reasons why this is true. In *Born Digital* (2008), the authors discuss the generation of digital natives as being those who were born after 1980. This particular subset of young people possess an uncanny ability to adapt to technological tools and have a seemingly built-in understanding of how they ought to fit them into their daily lives. The authors suggest that this phenomenon is a result of being born into a world where these technologies exist on a mainstream scale, unlike the world in which their parents were born.

The evolution of these technologies is so rapid, that it no longer just about being able to access a wealth of information in a single click. It is also no longer just about creation and identity exploration, but in fact, it is about networking. The concept of the "networked native" as introduced by Dr. Alan Greene:

> "Facebook and other social media platforms have been transforming the way people connect. The youth were the first adopters. They often know how to use the platform to the greatest advantage. It's easier, more efficient, more effective and more fun than traditional ways of connecting with young patients. Beyond this, when you do see them in the office it allows you to tailor the visit to be more productive" (Valenti, 2011).

Dr. Greene is one of a cohort of progressive physicians who believe that the Internet has the ability to connect us with one another to provide answers to health questions. His particular perspective is that given the networked nature of the most popular tools online (i.e. Facebook, Twitter, Google+, Foursquare, etc.), the next generation of young people, perhaps those born after 1990 ought to be considered "networked natives" – the Facebook generation.

This notion of "networked individualism" or basic interdependence on one's social network arises out of findings from the Pew Internet Research Project as summarized by director Lee Raine in a recent presentation:

- Social networks are important

- Social networks are differently composed

- Social networks perform different functions

- Social networks are more vivid and tied to creation of information/media

He continues to highlight the implications of this phenomenon in the health care space in that social networks can serve as second opinions, and that providers are still included in these social networks (Raine, 2012). While most of the research in this area has focused on adults' usage of the Internet for health-specific information and social support, the statistics imply the potential for adolescents to be just as, if not more empowered and engaged, especially those growing up with chronic conditions.

Demographically, most e-patients, that is those who utilize the Internet as a source of information and support, have a college degree, are parents with young children at home, married or living with a partner, and employed full time (Raine, 2012). Given what is known about this population of e-patients plus what research on adolescent Internet usage has shown, it can be inferred that adolescent e-patients do exist (Lenhart et al., 2011). However not much is known about them, but it is incredibly likely that they are active on Facebook above all other online platforms spurring engagement.

Facebook is the most popular social network at the moment overall, and is the primary social network utilized by adolescents. The appeal of Facebook to young people over other existing social networks such as Twitter, is the ability to control the information that certain groups of people can and cannot see. This fact defends the idea that adolescents familiar with the platform understand the risks involved with putting information online, which most likely correlates with their understanding of the risks involved with following medical information they find online as well. As with most new technologies, to understand the platform, one must immerse themselves in it, and with a platform as large and diverse as Facebook, it often takes a significant amount of time for a user to find their pocket of space within their own social network and also within the other communities of people that are built around everything from common musical interests to common diagnoses. The terminology used to describe activities on the platform is particularly intricate, and is outlined in the Facebook glossary to be found in Appendix B.

Generally speaking, a typical visit to Facebook for a seasoned user can be spurred by boredom, a notification they receive in their email inbox or on a mobile device, the urge to share, or just curiosity regarding a friend, event, or topic. When signing on to Facebook, the first page to appear is the newsfeed. The newsfeed is a chronologically organized set of updates, posts, and general activities on Facebook of one's friends, groups they belong to, and pages they "like." These posts can include status updates, interesting links to other websites or news articles, photos or videos, "likes", comments, events, or any changes to

their personal profiles regarding schools attended, occupations, interests, or relationship statuses. As a user scrolls through the posts, he or she quickly decides which information to pay attention to and which information to filter out based on who posted it, the content of the post, or if the post catches their eye with a particular keyword or striking photograph. The user might then read other's comments on that particular post, if there are any, might leave a comment themselves, might "like" the post, or might even share it on their own wall so that their friends could access the information as well. Facebook is truly an information superhighway, but the plus that it has over simple search engines like Google is that it is socially driven. That is, finding information on Facebook is typically connected to a human being who finds that information relevant to themselves or their social network. If a user has respect for that person whether it be professionally or simply because they always post the funniest YouTube videos, for example, that user will pay more attention to what that trusted person posts on Facebook.

For someone with a chronic illness, a visit to Facebook can be typical as described above, but it can also be driven by the search for health information and social support. An online survey of Facebook users with IBD specifically revealed that 82% of participants consult their personal physicians for information regarding new treatments, while 67% use websites, 33% see advice via Facebook, 30% refer to online forums, and 26% use face-to-face support groups (Kaminsky & Marticke, 2011). The complete survey results were surmised in the following statements:

1.   Patients are looking for useful tools that help them manage their disease, and don't currently feel like they have one and connecting with other patients is very important to survey respondents.

2.   Symptoms, treatment options and social situation advice are the key content that patients are looking for.

3.   Facebook is what most patients currently use to connect.

4.   Most patients are not currently very active in their respective IBD-related Facebook groups.

Given that the highest incentives for people with IBD to join IBD-specific Facebook groups is to find people with shared experiences and share ways to cope with IBD, these results provide insight into why someone with a chronic illness might look beyond their newsfeed and their friend's profile pages to delve into communities specific to their diagnosis.

Nature of Disease-Specific Communities

Vassilev et al. (2010) identified the following as characteristics of online support:

1.   Active engagement with online groups is more explicitly linked to a sense of support and well-being than offline support.

2.   A benefit to online communities is extended accessibility to advice.

3. Advice administered through virtual communities is contextualized through shared experiences, as opposed to the detached advice offered from professionals.

4. Online virtual support communities often resemble patient-led support groups.

5. Interaction between members of virtual communities is sustained only when a sense of familiarity and homogeneity is established between active participants (it is because of this that virtual interaction is sometimes seen as a substitute to face-to-face interaction).

These findings align with the trends that emerged in Plevinsky's (2011) qualitative work, which looked at the endangerment of support groups for youth with IBD in the context of the impact of an increasingly virtual world. Interviews were conducted with these youth and mental health clinicians and the codes that emerged were related to accessibility of the Internet and the value of shared experiences.

Greene et al. (2010) conducted a qualitative analysis of how people with diabetes communicate with Facebook. Findings indicated that they share clinical information, request disease-specific feedback, and receive emotional support in groups focused on managing diabetes. More specifically, analysis of the content of the posts confronted diabetic identity and the authenticity of an online community of people with diabetes. They identified themselves within the group as either new patients with diabetes or seasoned patients with diabetes, which

altered the nature of their post (i.e. new patients would ask for advice from seasoned patients). Greene et al. (2010) also observed some elements of digital citizenship in the form of exchanging information and etiquette emerging from the group members in response to some members posting about policies or issues with insurance that made it difficult for them to afford supplies or medications necessary to maintaining their health.

In a recent content analysis of breast cancer groups on Facebook, 620 groups were analyzed with a large majority geared toward fundraising efforts and raising awareness for the cause and only 7% to generate support for people affected by breast cancer. However, the support communities were found to have the most number of wall posts. When the purpose of the groups was analyzed via the title of the community and the content, it was found that nearly half were created to generate support for anyone affected by breast cancer. Perhaps most relevantly, of the creators of the group who had approximate age information available, 56% were college students, 37% were high school students, and 7% were recent college graduates indicating that all of the group creators with age information available were digital natives (Bender, Jimenez-Marroquin, & Jadad, 2011). Conclusions from this study touched on the fact that most support communities online are for people indirectly affected by breast cancer because Facebook groups and pages do reduce the anonymity of a stand-alone forum or discussion board. Also, these individuals tend to be younger and more tech-savvy than the older population that tends to be diagnosed with breast cancer.

It is interesting to note the contrast in findings between Greene et al.'s (2010) study and Bender et al.'s (2011) study. Diabetes is more similar to IBD in that it is a chronic condition that can be treated with lifestyle changes and medical interventions while breast cancer is very different in nature. Biologically, while all three of these conditions have genetic markers and are without cures, breast cancer is more closely linked to terminal outcomes than diabetes or IBD. Breast cancer cannot always be treated and often the treatment is simply surgical and even still can result in palliative care. Diabetes and IBD may be difficult to control and it may take an individual a while to find the treatment and lifestyle that lessen symptoms, however there are treatment options. This contrast between the etiologies of the two illnesses could account for the distinctions in the execution of their communities on Facebook. For example, chronic illnesses with complex treatment regiments that can be very personal such as diabetes and IBD might lead a newly diagnosed individual to the Internet so he or she can crowd-source opinions on a new treatment or a particular dietary plan while eliciting emotional support to adhere to it. Someone newly diagnosed with breast cancer might not necessarily feel as empowered to go online and talk about treatment options, especially because those treatment options tend to be very intimate. In light of this speculation, more qualitative work on illness-specific Facebook communities is required in order to accurately understand the culture and the benefits they can have within a particular illness population.

Chapter 4: Methods

The present study employed a short-term longitudinal evaluation of adolescent participants with inflammatory bowel disease (IBD). As previously indicated, this research was modeled in part after the work of Shepanski et al. (2005) in which researchers evaluated participants before and after attending Camp Oasis. In this project, the participants were evaluated once more after approximately two months of active membership and participation Facebook group with one another, and constructs beyond just health-related quality of life were examined. In an effort to enrich the project, the principal investigator (PI) also included brief ethnographic analyses of Camp Oasis and illness communities on Facebook and a detailed social network analysis of the participant's activity in the Facebook group.

Participants

Participants were recruited based on the following criteria: 1) diagnosed with Crohn's disease and or ulcerative colitis, 2) attending the full Camp Oasis Pennsylvania session in August, 3) be between the ages of 14 and 17 years old, and 4) have an active Facebook profile. Of the 89 campers contacted, 25 (31%) signed up to participate, 21 (84%) of who completed all three sets of evaluations (n=21). Of the 21 participants, 17 were female and 4 were male. Genders were unevenly distributed due to a few factors. First, most of the campers at Camp Oasis are female. There are often more female cabins, especially in the adolescent age group, which could be due to a variety of reasons. Female adolescents have a larger capacity to develop deeper social bonds than their male counterparts at

Camp Oasis that keep them coming back each summer. Also, female adolescents tend to be more active on social media sites, especially in terms of posting and tagging photos and videos of their friends (Lenhart et al., 2011). In terms of diagnosis, 4 participants were diagnosed with ulcerative colitis, while 17 had a diagnosis of Crohn's disease. Two participants reported being home schooled with 19 attending school regularly and were relatively evenly distributed across grade levels 9 through 12. Each participant was assigned a number so as to de-identify his or her results for the purpose of analysis and presentation.

Procedure

Participants and their parents were asked to complete assent and consent forms, respectively, allowing for the sharing of the questionnaire results and participation in the Facebook group. Throughout the week before Camp Oasis, participants were asked to complete the following questionnaires before the start of camp: (1) demographics, (2) social connectedness, (3) social support (Sarason, Sarason, Shearin, & Pierce, 1987), (4) IMPACT-III (Herbert, Griffiths, & Otley, 2002), and (5) Internet socialization (Ross, Ruff, Mackner, Vannatta, & Crandall, 2010). The questionnaires (Appendix C) were emailed to the participants via their parents and most participants completed them electronically while other preferred printing and mailing them or a telephone interview.

The Social Connectedness questionnaire was intended to measure how connected the participant felt with society. The questionnaire is comprised of twenty statements to which the participant responded on a scale from 1 to 5 (1: strongly disagree, 2: disagree, 3: mildly disagree, 4: mildly agree, 5: agree, and 6:

strongly agree). The sum of the responses was calculated for each participant Pre Camp Oasis, Post Camp Oasis, and Post Facebook to analyze how their connectedness changed over time. A higher score indicated a strong connectedness with society while a lower score indicated feelings of disconnectedness, or isolation. The scores could range from 20 to 120 with scores above 60 indicating connectedness and scores below 60 indicating isolation.

The Social Support Questionnaire (SSQ) was intended to measure social support by asking how many people in the participants' environments provide them with help or support. For each of the six circumstances described, participants were asked to identify all the people they knew who could help them in that particular circumstance, and were then asked to rate their satisfaction with their overall support in that same circumstance. The questionnaire resulted in social support number scores (SSN) and social support satisfaction (SSS) scores for each participant Pre Camp Oasis, Post Camp Oasis, and Post Facebook. A maximum of nine people could be identified for each question and satisfaction scores ranged from 1 to 6 (6: very satisfied, 5: fairly satisfied, 4: a little satisfied, 3: a little dissatisfied, 2: fairly dissatisfied, 1: very dissatisfied). For analysis, the average of the SSN and SSS scores were calculated for the whole group of participants. The higher the SSN and SSS scores were, the more social support and the higher social support satisfaction the participants reported having access to. It is important to note that these metrics measured universal support, not just support from others with IBD.

The IMPACT-III questionnaire is a quality of life questionnaire for children with IBD. The 35 questions are about life with Crohn's disease or ulcerative colitis, some of which deal with pain, feelings, or worries directly related to either of these diagnoses in order to measure the participants' health-related quality of life (HRQoL). Each question had 5 answers to choose from that varied depending on the question. The questionnaire was scored based on the paradigm provided by the creator and then reverse coded so that higher scores would indicate a better quality of life. The minimum score was 35 and the maximum score was 175. Scores were compiled for each participant Pre Camp Oasis, Post Camp Oasis, and Post Facebook. The scores were averaged for each time period as well to indicate overall change over time as well. Additionally, in an effort to gain a deeper understanding of what aspects of this construct were more intensely affected by the pediatric camping and Facebook experience, the overall HRQoL (QOL) scores were dissected into the following domains: (1) bowel symptoms (QOLBS), (2) systemic symptoms (QOLSS), (3) emotional functioning (QOLEF), (4) social functioning (QOLSF), (5) body image (QOLBI), and (6) feelings toward treatments/interventions (QOLTXI). Similarly to QOL, a higher score in each of these domains indicated a better quality of life in relation to each domain respectively.

The last evaluation was intended to measure Internet socialization and Facebook use. The questionnaire consisted of self-reported measures of how often the participant used the Internet and social media, how they use it to interact with others, how others use it to interact with them, etc. The questionnaire had both

qualitative and quantitative components, and concluded with a series of questions

regarding what the participants would like to see be a part of a social network for

young people with IBD.

The complete set of questionnaires was expected to take an average of 20

minutes to complete. While at camp, the overall culture of Camp Oasis was

observed and experienced, but the participants were not interviewed or contacted

during the week to allow for an optimal camp experience. At the culmination of

the week at Camp Oasis, participants were asked to complete a second identical

set of questionnaires within the week and upon completion were enrolled in a

"secret" Facebook group entitled "Continuing Camp Oasis" administrated by the

principal investigator of the present study. The structure of this study while

limited in its sophistication due to time constraints, was built to directly answer

the following research questions: 1a) Does attending Camp Oasis improve

adolescents' HRQoL, social support, and social connectedness? and 2a) Does

participating in a Facebook group diminish, maintain, or intensify the effects the

Camp Oasis experience may have on an adolescent's HRQoL, social support, and

social connectedness?

Continuing Camp Oasis

The intent of the Facebook group was to essentially continue the Camp

Oasis experience for the participants. It was developed as a way for them to

continue communicating with each other in a safe and secure space regarding any

topic, not just questions about living with IBD. A code of conduct (Appendix E)

was created based upon the previously developed online mentor guide for

ClubZora (Beals, 2008). The main principals of the code of conduct were to have respect for one another and to support the group members as evoked in the administrator's introductory post:

"hey all, feel free to use this space however you like. talk about camp, talk about life, talk about crohn's, talk about music..

post links, photos, anything at all really. have fun and enjoy. i might post every so often.. so don't ignore me!

also, if you could, anytime you read a post, please "like" it so i can ballpark how often you're visiting the group and reading what everyone has to say. there is a code of conduct that i'll be emailing out to your parents just so you're aware that this is a safe place and to be used as a supportive online space.

thanks all and happy social networking.. ☺" (Plevinsky, 2011, September 14).

For the first two weeks after the activation of the Facebook group, there were only two posts by the participants, indicating the need for the development of some sort of curriculum and manipulation by the administrator. In response to the inactivity, every other week the administrator would post a question related to living with IBD to spur some discussion. For example:

"do any of you guys blog? why/why not? If so and you want to share.. post the link!" (Plevinsky, 2011, September 18).

"would you guys use a [mobile application] to track your IBD? do any of you guys use one already?" (Plevinsky, 2011, October 18).

"hey all,

don't know if everyone saw this [link] on my wall, but i was

quoted in slide 11.. if you could tell the world, what would be the

one thing you would tell people not to say to patients with crohn's

or colitis?" (Plevinsky, 2011, October 20).

Overall, the extent of the facilitation of the administrator was to simply maintain

activity within the group and act as a member of the group as well. The

administrator's own experience with inflammatory bowel disease (IBD) allowed

her to become a trusted member of the group and thus helped to foster more open

communication between the other group members. New posts were introduced

rather sporadically as the administrator noticed activity within the group

dwindling. These periodic posts did help to spur discussion, but to keep it

interesting the administrator also introduced a word game where each member of

the group would comment on one post with a sentence that began with the last

word of the previously posted sentence. This was introduced because the

administrator noticed that the participants were interacting with one another on

Facebook much more via their individual profiles (i.e. posting on each other's

personal profiles, tagging photos of one another, posting links on each other's

walls, etc.). One of the reasons considered was that even though the participants

had all assented to partake in this research effort, there was no requirement for

how often they ought to post or how many times they should check the group

because of a lack of incentive for participation and also because the PI intended

for the group to mimic how the participants would normally participate in an

IBD-specific Facebook group with their peers. In addition to lack of incentive, perhaps the participants did not feel full ownership over the group space because it was named and created for the by the PI. There are many other IBD-specific Facebook groups in existence, including one of which that has been created by campers at this Camp Oasis location, that have a much higher membership and far more posting activity in response to posts regarding treatment options, who will be at the local area children's hospital that afternoon, or complaints and common symptoms.

Since results from interactions outside the group were not a part of this particular research effort, only activity that took place within the Continuing Camp Oasis group was analyzed. The reason for this was to protect the participant's privacy and allow them to have space on Facebook to interact with their friends from Camp Oasis and other places (i.e. school, sports teams, family members, etc.) without restriction. Therefore, conclusions from the social network analysis are only applicable to a Facebook group setting and are not necessarily indicative of all posting behavior on the social network. Finally, for ease of access and completion, the third and final identical set of questionnaires were transcribed into a Google form so that each participant could easily complete them online, and the participants were emailed a debriefing document (Appendix F) explaining the culmination of the group for research purposes.

Chapter 5: Analysis

The present study required multiple methods of data analysis given the nature of the primary hypotheses, secondary hypotheses, and constructs in

question: social support, social connectedness, health-related quality of life (HRQoL), Internet socialization, activity within the Facebook group, and the closeness and connectedness of the relationships between members via their activity with one another on Facebook. The social connectedness, social support, and IMPACT-III questionnaires could be scored numerically for analysis, and the Internet socialization and demographic measures were coded qualitatively. The data was further analyzed to discover significant patterns that arose between certain items asked on the quantitative measures that seemed to correlate with responses on the qualitative measures. Data analysis also included an in-depth social network analysis of "Continuing Camp Oasis" Facebook group using social network analysis to assess the frequency at which the participants posted and the connectedness between them. The following section will discuss both the quantitative and qualitative methods utilized to surmise the results from the present study in detail.

Questionnaire Analysis

Data collected from the questionnaires were entered into Microsoft Excel and SPSS for a comprehensive statistical analysis which included correlating all items within and between questionnaires and mean scores for each questionnaire over each of the three measurement points (Pre Camp Oasis, Post Camp Oasis, and Post Facebook). For each questionnaire, the mean scores were calculated for each of the measurement points and plotted over time to provide a clear display of how that particular measure changed overtime in the sample so as to address the research question pertaining to how the measures changed between each time

point. Because the diagnoses of Crohn's disease and ulcerative colitis are so similar as noted in the introduction, results were not distinguished based upon diagnosis. They were also not distinguished based on age or gender due to the majority of females in the sample.

In response to the secondary exploratory research questions, a correlation matrix revealed significant correlations between certain constructs. In particular, correlations between items within the Internet socialization questionnaire and the HRQoL, social connectedness, and social support questionnaires were found to be compelling based on results from the correlation matrix, previous literature, previous knowledge of the topic, and personal experience. In addition, correlations were revealed between items on the Internet socialization questionnaires and behavior patterns within the Facebook group setting including the social network analysis of the participant's activity on Facebook in general to be explained in the next section in response to the research questions pertaining to the nature of this population's use of social networking sites and implications for practice that may arise from these important findings.

Social Network Analysis

Social network analytic (SNA) software called Condor (Gloor & Zhao, 2004) was utilized to understand the connectedness between members in Continuing Camp Oasis to see if the group had truly fostered a sense of closeness between the participants electronically. Programs developed by students of Peter Gloor of the Massachusetts Institute of Technology Sloan School of Management's Center for Collective Intelligence were used to "crawl" the

Facebook networks of the participants in the group. This act of "crawling" aids in the collection of data from each of the participants' Facebook activities to determine degrees of connection and centrality, or position within the network in terms of influence (Gloor & Cooper, 2007). This information was transferred to a database format and then visualized using a tool called Condor. Using nodes and lines, the resulting displays were analyzed to identify the core members of the group as well as their connectedness with each other and other members of the group.

In addition to using the software to visualize the social network between participants in the study, further analysis of the group was conducted quantitatively, modeled from the methodology previously used in Plevinsky, Goldenhar, and Jackson's (2010) original exploratory effort analyzing IBD-specific Facebook groups and pages. That is the amount of likes, comments, and original posts were recorded for each participant. Comments were defined as commenting on another member's post while original posts were defined as the participant posting on the wall beginning a new thread of comments and/or likes. Overall engagement was defined as the sum of these three interactions, and was correlated with various items on the questionnaires in an effort to discover connections between hours reported being spent on social networking sites, or whether or not it was reported that social networking sites were a part of their everyday activity, for example.

Chapter 6: Results

The primary variables investigated in the present study were social support, social connectedness and inflammatory bowel disease (IBD)-specific health-related quality of life (HRQoL) over time. In an effort to address whether or not the hypothesis that HRQoL, social support, and social connectedness improved after attending Camp Oasis and then continued to improve after membership of a Facebook group called "Continuing Camp Oasis," each measure was taken Pre Camp Oasis, Post Camp Oasis, and Post Facebook. Social connectedness was measured on a Likert scale from 1-6 with response options ranging from "strongly disagree" to "strongly agree." The results (Table 1), recorded on average, indicated that before Camp Oasis participants scored 62.52. The scores slightly increased in this measure after the end of Camp Oasis (63.35) and then there was an increase in the average group score after being in the Facebook group (67.76). When paired t-tests were conducted between all three of the measurement points, none of these trends proved to be significant.

In looking at social support, two constructs were evaluated: (1) the number of people the participants look to for social support (SSN) and (2) how satisfied they are with the support they receive from them (SSS). From a theoretical perspective, this measure is particularly complex. While it is good for adolescents to have many people in their lives they feel supported by, the quality of those relationships is arguably more important than the quantity. For this paradigm, participants reported the initials of family, friends, coaches, teachers, or anyone in their lives who they felt supported by and then rated their satisfaction of that

support on a scale of 1-6 from "very dissatisfied" to "very satisfied." The number

of people and the satisfaction increased at similar rates after Camp Oasis (p=.281

and p=.227, respectively) and both increased even more post Facebook group

(p=.253 and p=.142, respectively), however the number of people increased more

intensely that the satisfaction with the relationships (Table 1). This indicates that

while the participants may have slightly expanded their social support networks in

the two months following Camp Oasis, the satisfaction with their social support

did not improve as much rendering Facebook as a potential way to gain breadth,

but not necessarily depth. The overall change between the Pre Camp Oasis and

Post Facebook measures in social support number was on the cusp of significance

and the overall change in social support satisfaction was significant (p=.077 and

p=.029) indicating potential effectiveness of an online Continuing Camp Oasis

program in conjunction with attendance at Camp Oasis.

The IMPACT-III questionnaire consisted of 35 items pertaining to overall

health-related quality of life (HRQoL), including IBD-specific questions.

Responses were reverse coded to reflect that the higher the score, the better the

health-related quality of life. The average overall HRQoL significantly changed

from 128.8 to 136.89 (p=.026) between the pre and post measures of Camp Oasis,

and decreased slightly, and insignificantly to 132.1 (p=.273) after the two months

following camp spent in the Facebook group (Table 2) When a paired t test was

conducted between pre Camp Oasis and post Facebook measures, the overall

increase was nearly significant at p=.059, also signifying the effectiveness of the

utilization of social networking as an extension of the in-person experience.

Bowel symptoms in people with IBD can be anything from frequent restroom usage, cramping, belly pain, an abnormal stool consistency, or urgency. In terms of quality of life related to these symptoms, participants reported a slight increase in HRQoL between the pre (26.35) and post (27.84) measures of Camp Oasis, and a slight decline at the post Facebook measure (26.75), (p=.135 and p=.438, respectively). Systemic symptoms of IBD tend to include fevers, mouth sores, joint pain, and fatigue. Quality of life related to systemic symptoms was lowest pre Camp Oasis (10.90) and increased to 11.63 post Camp Oasis, however, the QOL slightly decreased after the Facebook group to 11.05 (p=.117 and p=.419, respectively). Given that the overall change in this domain is less that one point, it is possible that the changes over time were a result of random error or due to the small range of scores. The paired t-test indicated that the changes over time in both of these domains were statistically insignificant. However, research has shown that there is a potential relationship between bowel and systemic symptoms in IBD. If repeated in a larger sample, these trends could be due in part to the social support that occurs at Camp Oasis, but given previous research and personal experience, this phenomenon is more likely due to the stress associated with the beginning of the school year combined with the lack of a controlled environment like Camp Oasis that ensures total adherence to treatment. It is also possible that the participants' symptoms did not change at all during this time period, but rather these respective environments affected their appraisal of their symptoms (Szigethy et al., 2005).

Quality of life in terms of emotional functioning showed a steady increase between the three measures taken pre Camp Oasis (23.15), post Camp Oasis (25.47), and post Facebook (26.05). Given that the quality of life increased significantly (p=.013) during the camp period and continued to escalate, however insignificantly (p=.4094) in the Facebook group reiterates the effectiveness of the camp experience of emotional functioning. The fact that the paired t-test conducted between Pre Camp Oasis and Post Facebook indicated statistical significance (p=.006) holds implications for the effectiveness of a Facebook group to continue to improve this construct. Quality of life related to social functioning increased between the pre (48.15) and post (49.58) Camp Oasis measures, however the paired t-test indicated that this increase was insignificant (p=.378). This was followed by a decrease in the two-month period after returning home from camp (45.67) which was significant at p=.004. Additionally, a paired t-test between Pre Camp Oasis and Post Facebook indicated a statistically significant decrease at p=.027. Since this measure encompasses all social functioning, not just that with peers with IBD; there are many factors that could play into this such as the reintegration into the home and family life, or the restarting of the school year. Also, the questions that make up the social functioning construct in the IMPACT-III are related to life in the context of school or the home where not all their peers are others with IBD. Historically, emotional and social functioning are linked, so it was expected that the two measures would correlate over time. However, during Camp Oasis, camp is the primary social environment for the participants while in the time period after

camp, Facebook is not their primary social environment. The significance of the social functioning construct is still important to note, but because of this is not necessarily an accurate measure of the effectiveness of online social support via Facebook.

Results in the domain of quality of life with regard to personal body image fluctuated over time. Pre Camp Oasis, the mean score was 9.2 with a nearly significant improvement to 10.47 post Camp Oasis (p=.055) and a slight, yet insignificant decline post Facebook to 10.38 (p=.916). As explained in Appendix B the Facebook experience for youth is driven largely by their profile pictures and photographs in which they can not only express themselves through self-portraits, but can also view how their friends do so (Schmitt, Dayanim, & Matthias, 2008). Perhaps future work ought to consider a more in-depth measure of body image to combat the potential measurement error that may have resulted from the very few questions dedicated to this domain in the IMPACT-III.

Other notable correlations between certain items were analyzed as well in terms of how particular items changed over time in order to provide a more compelling description of the participants' experiences over the course of the study. The Internet socialization measure (Ross et al., 2010) was crafted to further understand the participants' online activity. Participants reported spending an average of 15.67 hours per week on social networking sites pre Camp Oasis, 17.4 hours post Camp Oasis, and 17.74 post Facebook. The increase in the time spent online could have to do with the first measure having been taken before summer ended with the subsequent measures coinciding with school beginning. The

increase could also be explained by the fact that the campers use social media heavily in the time following camp to stay in touch with friends from Camp Oasis. This is further supported by the participants' post Facebook responses to how often they use social networking sites to keep in touch with friends from Camp Oasis (Figure 1). Of the 21 participants, 20 reported that they use social networking sites sometimes, fairly often, or often in order to keep in touch with friends from Camp Oasis.

Participants were also asked to report on their activity in terms of IBD-specific groups and pages specifically. When asked why they visit IBD-specific groups, 52.4% reported it was because "other people with this illness understand how I feel" while 9.52% reported it was because "the others on the site encourage me when times are tough." Only 4.76% of the participants reported it was because "it provides a lot of answers to my questions about the illness" and 28.57% reported other reasons (Figure 2). Given previous research and how people behave in illness-specific Facebook groups, this aligns with the idea that adolescents in the generation of digital and networked natives are generally aware that health information found on social networking sites is not necessarily reliable. Recall as Gray et al. (2005) reported, adolescents do report that the Internet is a primary source for information, but did not indicate social networks as a primary source of information. These results indicate that groups on social networks for adolescents may be regarded as a place for social support more so than health information, at least initially.

These results are particularly interesting in the context of how the participants reported that they use IBD-specific groups and pages. Of the 21 participants, 19 (90.48%) indicated that they read other people's comments and discussions, and of those 19, 5 (26.32%) reported rarely posting information and/or their thoughts while the remainder reported sometimes posting information and/or their thoughts (Figure 3). None of the participants reported that they post information and/or their thoughts on IBD-specific Facebook groups "fairly often" or "often," indicating that perhaps adolescents with chronic illnesses tend to lurk on these sites rather than actively participate. It is important to remember, however, that they still interact with the information and have the potential to be affected either negatively or positively by the information posted by slightly older users.

These behavior patterns can be further verified by the participants' responses to whether or not others use Facebook to ask them about IBD in general as well as their personal experience with IBD. The majority of participants reported that this happens "never," "rarely," or "sometimes." Only 4.76% reported that it happens "fairly often." These results may be a reflection of their own behavior in IBD-specific groups, but also may be a function of how hard they try and keep their IBD a secret and to how many IBD-specific Facebook groups they belong. The construct was also examined over time. The amount of participants who reported that they tried hard to keep their IBD a secret decreased between the pre and post measures of Camp Oasis and the Facebook group. The majority of participants reported that they "try a little", with the amount of

participants who reported that they "don't try much" steadily increased over time. There was no significant correlation found between this construct and the individual participant's membership of IBD-specific Facebook groups, however (Figure 4).

Another pattern that resulted from the Camp Oasis and Continuing Camp Oasis experiences was the ease at which participants reported it was to make friends because of their IBD. Over time, the percentage of participants who reported that it was "not at all harder" to make friends because of their IBD increased from 76% to 80.95%. The percentage of participants who reported it being "a little harder" decreased from 23.81% to 14.29% while those who reported it being "quite a bit harder" remained at around 4%. This indicates that both the social environments provided at Camp Oasis and in Continuing Camp Oasis helped participants who were having slight difficulty making friends to realize that it is not at all harder to do so with IBD.

The activity within the Facebook group was calculated based on number of likes, comments, and original posts by the members. For analysis purposes, only actions performed by participants were recorded even though the administrator played an active role in eliciting participation within the group as previous indicated. All participants were given an equal opportunity to respond to posts by the administrator and posts were non-specific in that all participants could respond to them if they so desired. A complete total of 96 individual actions were recorded, 46 (47.91%) of which were likes, 41 (42.71%) of which were comments, and 9 (9.38%) of which were original posts by group members. Most

members engaged with the group an average of 1-2 times, with four participants outlying at 12, 15, 20, and 21 interactions with the group in the duration of Continuing Camp Oasis. Of these four participants, all were female and for three of the four participants, the majority of their interactions with the group were "likes," while they each only posted 1-2 original posts. Finally, eight of the participants did not post at all. However, this does not mean that they weren't lurking on the group and engaging with the information posted by other group members. In an effort to explain this lurking behavior with other constructs collected on the questionnaires, all participants were tracked in the social network analysis to look at their connectedness with one another.

Other statistical analyses revealed various significant correlations between constructs both within and between questionnaires as well. Gender was found to be only significantly correlated with bowel symptoms post Facebook ($r = .473$, $p = .05$), emotional functioning pre Camp Oasis ($r = .455$, $p = .05$), and emotional functioning post Facebook ($r = .554$, $p = .01$). Hours per week spent on social networking sites were significantly correlated with quality of life related to perception of treatments and interventions ($r = -.473$, $p = .05$) and if the participant was home schooled ($r = .607$, $p = .01$). The correlation matrix of all of the data also displayed that home schooling was significantly correlated with quality of life related to perception of treatments and interventions both pre Camp Oasis ($r = -.523$, $p = .05$) and post Facebook ($r = -.518$, $p = .05$) suggesting that the relatively strong correlation between hours per week spent on social networking sites and home schooling may have a combined influence on one's

perception of treatments and interventions, or perhaps that more severe treatments and interventions are reserved for more seriously ill youth who may tend to be homeschooled because of their illness severity. This was not further examined in this sample because only two participants reported being homeschooled, however, these preliminary findings do imply different clinical considerations for teens with IBD who are home schooled than for those who attend school, especially in light of recent research findings suggesting that academic achievement and performance in these adolescents is affected by absences from school (Mackner, Bickmeier, & Crandall, 2012).

Social connectedness measured pre Camp Oasis was correlated with the social support number pre Camp Oasis (r = .455, p = .05) and social support satisfaction pre Camp Oasis (r = .773, p = .01) signifying the relation between the social connectedness and social support measures utilized in the present study. Only post Facebook was social connectedness correlated significantly with the following constructs of the quality of life measure: overall quality of life post Facebook (r = -.447, p = .05), bowel symptoms post Facebook (r = -.557, p = .05), systemic symptoms pre Camp Oasis (r = -.517, p = .05), systemic symptoms post Camp Oasis (r = -.514, p = .05), and systemic symptoms (r = -.536, p = .05). As previously defined, systemic symptoms refer to those that are not directly related to IBD such as fevers, fatigue, loss of appetite, etc. Systemic symptoms can result from psychosocial maladjustment to having a chronic illness such as IBD, therefore the positive significant correlation between social connectedness and quality of life related to systemic symptoms implies the role that social

connectedness can have on psychosocial difficulties in the context of chronic illness in adolescence.

Social support pre Camp Oasis was only correlated with bowel symptoms post Facebook at r = .462, p = .05 while social support post Camp Oasis and post Facebook were correlated with more constructs of quality of life such as overall quality of life (QOL), social functioning (QOLSF), body image (QOLBI), perceptions of treatments and interventions (QOLTXI), and systemic symptoms (QOLSS) as depicted in Table 3.

Given the limited activity within the Facebook group, the correlation between likes, comments, original posts, and overall activity was only significant at the .01 level. All activities were positively correlated with their related counterparts, however comments were found to be negatively correlated with both social connectedness pre Camp Oasis (r = -.515, p = .05) and social support post Facebook (r = -.487, p = .05). In an effort to further evaluate the activity within the Facebook group, social network analysis was used to visually depict the connectivity of the participants through measuring their activity on Facebook with one another both within and beyond the group.

Figure 5 displays the output from Condor when looking at all of the group members and their Facebook activity. From the figure, three primary networks can be identified. The blurred regions of the figure are where names were listed indicating the most influential members of each of the three networks. The network in the upper right hand corner is not very interconnected within itself and the distance from the other two clusters at which it lies indicates that the users in

this cluster were not connected with the other members of the group on Facebook. The cluster in the lower left hand corner is also not very interconnected with itself, however it's relative distance to the cluster closer to the middle of the figure indicates more interaction between those participants and the core group than the participants mapped in the cluster in the upper left hand corner. The cluster in the middle represents a very networked group as indicated by the crossing and overlapping of the lines, which represent the connections between users.

In further interpreting Figure 5, participants in each cluster behaved within the group as the posts, comments, and "likes" would suggest. Of the participants placed in the cluster in the upper right hand corner, none had more than two interactions within Continuing Camp Oasis. These participants also reported lower times spent on social networking sites per week, potentially indicating an overall lower engagement in Facebook and interacting on social media altogether. Participants placed in the lower left hand cluster also only posted a maximum of two times on Continuing Camp Oasis as well, however, they reported spending a significant amount of time on Facebook and social networking sites, which leads to the idea that most of their activity on Facebook occurs either on their own profile or on their friends' walls and not in groups like Continuing Camp Oasis. The participants placed in the well-networked cluster were those who posted at least ten times within Continuing Camp Oasis indicating that they were not only active within the group, but still interact with one another outside the group as well. Even though these participants were charted as being very networked and

engaged with one another, they actually reported rather low hours per week spent on social networking sites with a mean of 4.63 hours per week. This could be indicative of a few trends regarding their behavior on Facebook. For example, they could be using their time on Facebook efficiently and only to interact with people they do not see everyday, such as friends from Camp Oasis. On the other hand, these participants could also have just been checking into Facebook and posting on the group because they were a part of this study. Follow-up interview questions would do well to address potential engagement bias.

Chapter 7: Discussion

Results from the present study suggest that within the sample, both the Camp Oasis program and participation in Continuing Camp Oasis (CCO) elicited improvements in social connectedness, social support, and health-related quality of life. In particular, the improvements in social connectedness in contrast with the fluctuation in social support number and satisfaction over time suggest that perhaps Facebook is a better tool for social connectedness and breadth of social relationships, but not necessarily as effective for depth of social relationships. Additionally, emotional functioning was correlated with bowel and systemic symptoms, suggesting a link between the two that could potentially be mediated by social support. Finally, there was an interesting correlation between home-schooling, hours spend on social networking sites per week, and feelings toward treatment and interventions prompting a research question regarding how these factors effect one another.

Given these trends, both Camp Oasis and virtual communities such as groups on Facebook can be considered viable supplemental interventions for adolescents who attend Camp Oasis and are struggling with both physical and psychosocial distress as a result of IBD. As predicted, these results further clarify the results reported in Shepanski et al.'s (2005) pre and post work with Camp Oasis and takes into account the increasingly virtual nature of social connections between young people with IBD. The following discussion will identify limitations of the present study, address potential interpretations for observed results, and highlight the future research questions that emerged from this thesis.

Social Support and Social Connectedness

The results that emerged from the social support evaluation suggested that over time, participants identified more people on average who they can look to for support in difficult situations, however, their satisfaction with these relationships decreased during the time spent in the Facebook group after Camp Oasis. This implies that perhaps Facebook is a good way for adolescents to have more immediate access to a large number of people for support, but may want more from these relationships, something that an in-person relationship might be better able to offer. When interpreting these results to mean that online support is only good for breadth while in-person support offers more by way of depth in terms of social support, it is important to consider the nature of the questionnaire administered. Participants were asked to simply report the initials of people who they look to for social support and then rate their satisfaction level with those individuals. Future efforts utilizing this measure ought to have the participants

specify how they interact with each individual or how they access social support from them the majority of the time. This information would give researchers a sense of whether or not social support was being elicited from a virtual source or if it was available in person at the various times of measurement. This deeper understanding would be valuable because researchers not only would be able to interpret if breadth is simply a function of an online medium of social support, but also if satisfaction is linked to one medium over the other. In the present study, the only true significant change over time in this domain was in social support satisfaction between pre Camp Oasis and post Facebook, which implies that perhaps an in-person experience that is extended by participation in an online community can foster the social relationships developed at a program like Camp Oasis.

Even in light of the significant correlations between the social support and social connectedness measures pre Camp Oasis, the social connectedness measure suggested improvement overall on average with a more intense increase between the post Camp Oasis and post Facebook measures, however statistically insignificant. Still considering the results, perhaps online relationships foster a stronger sense of connectedness than an environment like Camp Oasis. This could in part be because while Camp Oasis provides a fantastic platform for youth with IBD to connect with one another, for some it can be an isolating environment from their friends and family. The present study did not specify to the participants to only think about others with IBD when completing the social support or social connectedness measures because then the results would not depict reality. While

others with IBD may be an important part of their social environments, an adolescent with IBD also receives social support from their families, teachers, mentors, and peers from their schools and communities. Perhaps the reason for the difference in increase could be attributed to the participants having returned to their home environments and immersing themselves in their lives combined with the connectedness that carried over from the Camp Oasis experience. Or perhaps Facebook does in fact have an impact on social connectedness. It is, after all, a network in itself. Future work ought to explore how to isolate the effects of social networking longitudinally in adolescents, but researchers may find themselves hard-pressed to find anyone who isn't on Facebook already.

Health-Related Quality of Life (HRQoL)

The potential explanations for the trend observed in the domain of health-related quality of life are practically endless. Most importantly, the end result was an overall suggested improvement, even though the changes were statistically insignificant. As with the previously discussed measures, considering the home and school environment is paramount, the effects of which can be better explained when dissecting the HRQoL measure into it's six constructs: (1) bowel symptoms, (2) systemic symptoms. (3) emotional functioning, (4) social functioning, (5) body image, and (6) perception of treatment and interventions (Figure 6). The only construct that that steadily increased overtime was emotional functioning while the rest of the constructs peaked post Camp Oasis and slightly declined post Facebook. The changes that occurred over time in emotional functioning were statistically significant as well. This construct was explored in children and

adolescents with medically unexplained chronic pain in the context of developing

an intervention. In this study, researchers defined the construct as a child's skill in

identifying and symbolically communicating and managing pain and other

negative body states (Kozlowska and Khan, 2011). Given that emotional

functioning bears a clear theoretical connection to physical symptoms, or bowel

and systemic symptoms as identified in the IMPACT-III, participants in the

present study did report slight overall improvements in these two areas. However,

they also reported that their quality of life in relation to the two peaked post Camp

Oasis.

First, the environmental reasons for this could be because of the Camp

Oasis environment. As previously mentioned in the brief ethnography of Camp

Oasis, the campers are highly monitored and there is very little risk of accidental

or volitional nonadherence to medication. Furthermore, the campers are in

constant care of trained counselors, nurses, and doctors who make sure they drink

enough water during the day and get enough rest. Not all the participants may

have this luxury or this discipline in their home environments, which is why

bowel and systemic symptoms could have exacerbated in that time period.

Second, people can also get sick and because IBD is a biological illness and due

to the small sample size, it is possible that perhaps some of the participants were

simply not doing well. The PI did not have access to any of the participants'

medical records and instead chose to identify HRQoL as the measurement for

psychosocial wellness. An objective measurement of illness activity may have

been helpful in analysis, but was not accessible at the time. Finally, the return to

the home environment could elicit stress or anxiety of starting a new school year, which has been related to physical symptoms of IBD. However, in spite of this, the fact that the participants reported that their emotional functioning, or ability to cope with these more severe bowel and systemic symptoms improved helps to support the fact that both in-person and online social support truly can have an impact on quality of life. This interpretation holds implications in line with personal experience that there ought to be more future work on the resilience of adolescents with IBD.

A similar trend was seen in body image, social functioning, and perception of treatment and interventions in that the construct improved over time, but still decreased between post Camp Oasis and post Facebook measures. The results regarding body image indicate statistically significant overall improvement in the area with the return to the participants' normal home and school environments being a possible justification for the slight decline post Facebook. However, it is important to note the increase over the camp period and that most of that increase was maintained over the time period could be explained by the visual nature of the medium. It is also important to consider the limitations of having such a small scoring scale in these domains similarly to the scale for questions regarding bowel symptoms. Again, these decreases could be explained by the return to the home and school environment for similar reasons as previously discussed, especially because prior research has shown how interconnected these particular constructs can be in this population. However, in terms of statistical significance, perception of treatment and interventions was found to be strongly correlated with both

whether or not the participant was home schooled as well as hours spent on social networking sites per week.

The trends experienced in the construct of feelings toward treatment and interventions were almost as expected. There was a very slight improvement in quality of life related to treatments and interventions between the pre and post Camp Oasis measures and this was followed by an even more intense improvement in the period following Camp Oasis. These results are interesting because there are many aspects of the Camp Oasis experience and the return to school that could have affected the trend described. The reason for the increase in this domain of quality of life may have been minimal because this domain may be driven by both the participants' expectations rather than just social support. To clarify, meeting other campers who undergo similar treatments and interventions may have helped them to realize that they may have been catastrophizing their own treatment regiment. On the other hand, the camp experience does expose youth with different illness severities to one another, which could affect their perception of their own treatment regiment in relation to their fellow campers. While home schooling and hours spend on social networking sites per week were correlated independently of this particular construct of HRQoL, it was still intriguing that of all the six constructs, this one was correlated with time spent social networking.

There are few more apparent reasons why this construct correlates with home schooling. Youth with IBD who are home schooled tend to have very severe disease and may even be on treatments or interventions that require them

to spend more time in the home such as nasal-gastrointestinal tube feedings, frequent hospitalizations, etc. An individual undergoing more invasive and more intense treatments may report that they inhibit their quality of life more than someone who only takes oral medication and is able to attend school regularly. However, the fact that perception of treatment and interventions was also positively correlated with hours spent on social networking sites could have implications for the fact that if participants were using Facebook to browse IBD-specific groups and pages as they reported, then perhaps they were reading information on treatments and interventions that helped them to realize certain therapies don't need to impede their quality of life.

In this arena, an interesting research question to explore would be the connections and directional effects of home schooling, hours per week spent on social networking sites, and quality of life with regards to treatment and interventions. This information would be valuable across pediatric illness populations, but especially in IBD given recent research on achievement and missed school. It was recently found that adolescents with IBD do tend to miss a lot of school both directly because of their treatment, but also because of internalizing problems that can arise in these youth such as depression or other psychosocial distresses which can be fueled by feelings of isolation, and thus combatted by social support (Mackner, Bickmeier, & Crandall, 2012). And also in that same vein, it would be beneficial for future work to address directional effects of social support and overall HRQoL so that the pediatric psychology

community can make more targeted recommendations for increasing the accessibility of social support in-person and online.

Limitations

The present study had a small sample size (n = 21). Therefore, the results found within this thesis are not generalizable to the majority of the population of adolescents with IBD, yet the findings still contribute to the body of work being done with this population in the area of social support in person and online. In addition to the sample size being small, the genders of the participants were not optimally distributed, rendering the results indicative of female adolescents with IBD more so than males. Statistical analyses with such a small sample did not show particularly strong correlations, however a few emerged a significant and were discussed in the context of previous knowledge, prior research, and personal experience.

Time constraints were also a limitation when designing the study. Given the nature of the Eliot-Pearson Department of Child Development's thesis timeline, the PI was only able to conduct this study over a period of three months. If future researchers were to repeat the present study, they ought to repeat the measures a fourth time perhaps six months after Camp Oasis. Because of these time limits, Continuing Camp Oasis itself did not produce enough content for a comprehensive content analysis of the wall posts.

Finally, there were no incentives to participation in this research for the participants. The PI relied on the intrinsic motivation of the participants to complete the surveys in a timely manner and remain active members within

Continuing Camp Oasis throughout the course of the study. However, the PI did share a personal relationship with most of the participants, as she has been a volunteer counselor and leadership staff member for the past six summers at this particular Camp Oasis location. Therefore, there may have been some recruitment bias involved in participants joining the study, completing the questionnaires, and posting in Continuing Camp Oasis due to familiarity with the PI. The PI also acted as the facilitator for Continuing Camp Oasis, but only posted prompts and allowed participants to respond freely without manipulation. The familiarity between the PI and the participants had no effect on data interpretation, as the results were de-identified for analysis purposes. However, the participants' willingness to join the research may characterize them as more apt to respond to social interventions like a pediatric camping experience or an online Facebook group.

Chapter 8: Conclusion

Social networking is becoming the primary way in which adolescents today are accessing information and one another. As discussed earlier, youth growing up in a society where social technologies are paramount to daily functioning are being known as networked natives, rather than the digital natives born in the 1980s. This domain is particularly important to explore in the context of adolescent development and pediatric psychology as there are already many risk factors and social challenges to this stage of development, especially in those with health issues like chronic illnesses such as inflammatory bowel disease (IBD). Adolescent development involves identity and social development, two

processes that have been completely overhauled by the introduction of personal homepages and the concept of the online profile on sites like Facebook.

Naturally, parents and policymakers alike are concerned about online safety, and most recently, online harassment or "cyber-bullying." Developmental theorists have determined that adolescents are prone to risk behavior because of all of the things going on both biologically and psychologically. However, Lenhart et al.'s (2011) report on the topic actually reports that the majority of teens online today do not engage in risky behavior. They are rather aware of the risks involved and as a result of being so computer savvy, are privy to the intricacy of privacy settings on sites like Facebook so that they can protect themselves online. A new dimension of risk factors and safety concerns emerges when looking at adolescents with chronic conditions, specifically IBD, for which there is no known cure.

As the world becomes increasingly virtual, the health care space is trying to keep up with the explosion of personal technologies and researchers, developers, patients, and physicians are buzzing with the potential to use this innovation to improve clinical outcomes. One example is the Collaborative Chronic Care Network (C3N Project): a group of dedicated individuals representing all of these constituencies to make an impact on care for youth with IBD. The C3N Project was built on the idea that collaboration and passion can spur innovation in the health care space, so long as youth and their families are heavily involved in the process. In addition to partially supporting the present study, they oversee dozens of innovations ranging from tracking passive and

patient-reported outcomes on mobile devices so that they can engage in N of 1 experiments with their doctors to social networking platforms that match individuals with one another based on symptoms, treatments, and even taste in music.

Results from the present study will serve to inform these innovations and interventions developed by the C3N Project and ought to similarly inform how parents and pediatric psychologists ought to address how adolescents with chronic illness can best benefit from social support in-person and online. If one has the ability to attend a camp program like Camp Oasis, the experience can by life changing and can have a profoundly positive effect on an adolescent experiencing feelings of isolation or mild depression in light of their diagnosis or symptoms. When Camp Oasis is not a viable option, however, virtual support seems to be the next best thing. An ideal intervention would be a combination of the two as seen with the participants in this study, but if online support is the only option; it's not a bad option by any means. It is important to address the fact that not all health information out there will be quality information, and that it is important to keep the channels of communication open between the youth, parents, and physician if the youth shows interest in exploring an alternative treatment plan based on information found online.

Previous studies have done their best to analyze the content occurring on the walls of illness-specific Facebook groups to try and understand how much of the content is reliable, encouraging, and posted by actual individuals with a particular chronic illness. Due to Facebook's own security settings, social network

analytics has not come this far, so researchers with IRB approval and consent from all members of a Facebook group or page can conduct a content analysis of posts through qualitative coding procedures, which are not ideal for a large body of posts. The methodologies used in Plevinsky, Goldenhar, and Jackson (2011) and Bender, Jimenez-Marroquin, and Jadad (2011) attempted this to try and paint a cohesive picture of the activity occurring in illness-specific Facebook groups. Trends seem to suggest a very high comfort level with sharing information about treatments, lifestyle, and personal anecdotes as a way of eliciting social support and providing it to others. On the whole, intentions are good, but this does not eliminate the concern arisen by pharmaceutical companies promoting their products in these public spaces or by individuals boasting holistic remedies that may not be FDA-approved.

It is especially important to be aware of this risk in adolescents. Given the nature of this stage of development, treatment adherence tends to be more of a concern, especially as adolescents may begin to have a deeper cognitive understanding of unpleasant side effects of certain medications while simultaneously increasing in autonomy. Some adolescents are completely responsible for their medical regiments while others are still kept under close watch. This of course is at the parents' discretion and is currently a research topic being explored under the domain of transition to adult care. Due to the lack of previous research on this topic, physicians are currently exploring what comprises a successful transition from pediatric to adolescent to adult care in various chronic illness populations, including IBD. Exploring this will provide implications for

programming and the use of social technologies in aiding this often difficult and trying process.

Social networking and online communication between physicians and their young patients can not only make a transition to adult care smoother, but can also help strengthen the doctor-patient relationship. Using a medium that youth are comfortable with such as texting or e-mail might help them to better express themselves and their symptoms. Research and personal experience has shown that those with IBD tend to underreport their symptoms either because they don't want to be limited by their illness or they don't want to have to face the associated invasive procedures and complicated treatment regiments that often accompany active disease. However, this information is important to improving clinical outcomes, which as discussed can have a large impact on quality of life.

In sum, the purpose of this thesis was to delve into how adolescents with IBD use social networking sites like Facebook while taking into account the impact that Camp Oasis and Facebook groups can have on social support, social connectedness, and health-related quality of life in this population. This effort was meant as a first attempt at exploring the idea that perhaps online social support ought to be considered as a viable form of social support for the next generation of young people with IBD. The PI hopes to expand upon this work to incorporate a more long-term evaluation and a more complex research design to get at specifically what characteristics of an individual with pediatric IBD make them more apt to benefit from online communities and what aspects of online communities can stand up to the tried and true effectiveness of in-person social

support so that program developers can learn from and emphasize those elements

in new interventions.

Appendix A

Camp Oasis Schedule

Appendix B

Facebook Glossary of Terms

Chat: The chat function on Facebook was created to mimic instant messaging application such as AOL Instant Messenger and Google Chat. Expanding the chat window while logged onto Facebook allows you to see which of one's Facebook friends are currently also logged onto Facebook by displaying a green dot next to their name. The function allows you to send your online friends messages in real time while still browsing Facebook.

Comment: Comments can be posted as responses to most things posted on Facebook (i.e. links, photos, videos, new friendships, changes in jobs, changes in relationship statuses, etc.). In a comment, a user can express their thoughts on any number of these things in either encouraging or negative ways. Comments can be liked by other users as well.

Event: An event is created by a user to invite guests to any kind of event, in-person or otherwise. The creator or administrator of the event has the power to control the privacy level of the event as well as which other users are invited to join or attend. The event can be customized with it's own identifying photograph, and photographs can be added to an album within the event.

Friend: A friend is another user on Facebook that one particular user has identified as such. Being friends with another user on Facebook allows one to see the content on their profile that one allows given the privacy level they have categorized that friend within. Friending someone involves adding a user and then their updates and posts will appear on one's newsfeed as a result of the online relationship, however, one can remove a friend from their newsfeed if desired. One can also unfriend a user for any reason at any time (i.e. frivolous posting, annoyance with that user, or simply to streamline their newsfeed).

Friend request: A friend request is the act of adding another user as one's friend on Facebook. Most often a friend request results from having met another user in person, but sometimes it can result from search results for old friends or perhaps coming across another user within a group who may share similar interests or opinions in music or politics, for example. Brief personal messages can be added to friend requests as well to put the friend request into context.

Group: A Facebook group is created by a user to compile users with similar interests in a cohort within Facebook. Groups tend to rally around causes related to health, politics, policy, or other meaningful topics. Users will join groups based on their interests or if they have friends who are members of those groups. Within groups there is a wall where users can post, comment on posts, and like posts. Group members are not necessarily friends with one another, but if they find that

they have similar opinions or interests, they may friend request one another and become friends.

Likes: Likes are a very simple and easy way for users to engage with posts on Facebook. Any post or activity on Facebook that has the "Like" button below it can be liked by a user. Liking a post can show that the user genuinely likes a certain post or at least agrees with the post. The more likes a post receives, the more it is regarded by Facebook as an important post and the newsfeed functions so that these posts are at the top of one's screen when they log on to be sure they see that post.

Message: The message function has since been embedded into the chat function on Facebook. That is, a message is simply a chat that has been sent to a user not currently logged onto Facebook. Users can attach links or photos to messages, and messages can be sent to multiple users at once.

Newsfeed: The newsfeed is the page users are taken to upon logging onto Facebook. One's newsfeed displays all activity on Facebook that happens within groups and pages one is a member of as well as activity that their friends have been posting such as links, comments, photos, videos, etc. It is organized so that along the left hand column you can find shortcuts to the message inbox, the events page, and active groups and pages of which the user is a member. The center of the page is where you can see updates from one's friends, groups, and pages. The right hand column features a live stream of activity occurring within one's larger network, that is, users who interact with one's friends. This column also features reminders of one's friends' birthdays and upcoming events they've been invited to or have already agreed to attend.

Notifications: Notifications are how Facebook alerts users to activity that pertains to them personally (i.e. event invitations, tagging, wall posts, comments or likes on their posts, etc.) Users can customize what activities they'd like to be notified of. Some users allow notifications to come through their personal email inboxes while others simply check Facebook regularly or have notifications come through the Facebook application on their mobile devices.

Page: A page is similar to a group, however rather than being a member, users are considered "fans" and join that page via "liking" it. Pages do not have walls, they are platform for which the brand, company, or individual user who owns that page can post content and information they want their fans to see.

Photos: Facebook is driven largely be photographs. Users have the option to choose photos of anything for their profile photo, which is situated at the top left hand corner of the profile page. Most users choose to post photos of themselves, but not all. A thumbnail of this photo appears next to one's name when they comment or post anything anywhere on Facebook. There is also an option to upload a cover photo to be displayed at the top of one's personal profile to further

customize the profile page. Facebook also has a function where one can upload photo albums in which users can tag their friends if they are pictured in the photo. On the personal profile, photos that have been tagged of that user appear filed in chronological order for other users to view.

Poke: The act of poking someone on Facebook has changed in meaning over time and is not as widely used as it was when it was first introduced. When a user visits a friend's profile, they have the option to "poke" that person simply to get their attention.

Post: A Facebook post can be extremely simple as a text-only status update or can include a photo, a link to an external website, or a video. Users can post things on their own walls, in groups, or on their friends' walls. Posts are the primary activity that happens on Facebook. Posts can be commented on, liked, and shared between users and drive interaction between users and can be used as a measure of engagement and connectedness in social network analysis methodology.

Profile (also known as Timeline): The profile page is a user's personal page where they can choose their profile photo and their cover photo. They can share as much or as little information about themselves with regard to their birthdate, schooling, and work information. The profile page is what other users see when they click on one's name. Using privacy settings, users may choose to limit what other users can see, for instance, if one may only allow their friends to see their complete profile.

Privacy settings: Privacy settings have been made more and more detailed and complex in response to demand from the users. It is complicated, but if a user is particularly concerned with who sees the information they post on Facebook, there are countless combinations of privacy settings that allow certain groups or categories of users to see more than others.

Sharing: The share button is an option not only within Facebook but also throughout the web. Sharing within Facebook involves taking a post from a friend and sharing it either on your own wall or on the wall of a friend. Many external websites offer this same option so that users can easily and almost seamlessly share their content on their own walls or their friends' walls.

Status update: A status update allows users to express themselves on their own profile pages. Status updates are posted in the newsfeeds of their friends, so often users will post about what they're doing at that moment or what they think about things. Status updates can include photos, links, or videos as well.

Tagging: Tagging used to be reserved for photos, that is being able to link a user's profile to their photograph on Facebook. However, now users can be tagged by typing "@" before their full name in a post or a status update and Facebook will link their name to their personal profile. That user will also receive a notification

that their name has been linked to a post. Privacy settings can dictate that users not be tagged in posts at all.

Appendix C

Promotional Material and Parent Letter

Is your child attending CCFA's Camp Oasis this summer?
Is your son or daughter ALWAYS on Facebook?

If so, then you and your child may be eligible to participate in an
original research study in conjunction with Tufts University to assess if
the long-lasting friendships your child makes at camp this summer can
be effectively maintained online throughout the school year.

In this packet are a few forms for both you and your child to fill out
before they get to camp, and they can be emailed back or mailed to:
Jill Plevinsky

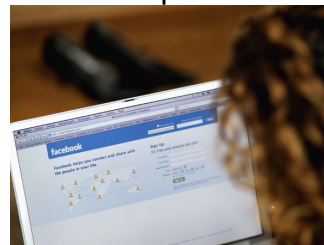If you have any questions about this study, please contact the
principal investigator **Jill Plevinsky** at ▮▮▮▮▮▮▮▮ or
continuingcampoasis@gmail.com.

*Please note that attendance at Camp Oasis this summer does not
require that your child participate in this study, however it does
require that your child have or create a Facebook profile.

From camp...   To computer...

Jill M. Plevinsky

continuingcampoasis@gmail.com

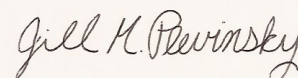June 9, 2011

To Whom It May Concern:

My name is Jill Plevinsky and I am currently working toward my graduate degree in child development at Tufts University. In completing my degree, I am conducting an original research study for which I am requesting support from the Crohn's and Colitis Foundation of America. My research interests include working with adolescents with inflammatory bowel disease, more specifically, how they maintain the relationships made at Camp Oasis via Facebook. This particular study will measure social support, social connectedness, Internet socialization and Facebook use, and IBD-specific health-related quality of life pre- and post-camp, and once more after a couple of months of participation in a private and moderated IBD-specific Facebook administrated by myself. Comparing the changes that occur in these measurements between attending camp and then again after participating in the Facebook group will help to support my hopeful hypothesis that online social support has the potential to have the same positive effects as a week at Camp Oasis.

I was diagnosed with Crohn's disease and age seven and have been involved with the CCFA ever since through bowl-a-thons, a term as the first youth ambassador for my local chapter, Take Steps, Team Challenge, and serving as the inaugural co-chair of the National Youth Leadership Council. I have met so many young patients with this disease and I know first-hand just how difficult it can be, which is why I was inspired to work toward a career in psychology, specifically focusing on this patient population. This research builds upon previous work done regarding the positive psychosocial influences of pediatric camping within IBD and beyond. It also builds upon the idea that social support and shared experiences with peers can alleviate much of the stress, anxiety, and embarrassment that may accompany having a chronic illness such as IBD. Results from this study could potentially aid in how mental health professionals reach out to their patients and connect them with one another, especially those patients that might not have access to a strong IBD community or cannot attend Camp Oasis. Results can also help provide recommendations to develop a safe and secure mechanism for these patients to connect and get reputable health information as well.

My advisor at the Eliot-Pearson Department of Child Development at Tufts University, Marina Bers, will be overseeing my work. Regarding any further questions you may have, Dr. Bers can be reached via email at marina.bers@tufts.edu. Also, you may contact the Tufts University IRB at (617) 627-3417.

Attached you will find the parental consent and assent forms. Thank you in advance for your consideration, and please contact me if you have any questions or concerns.

Sincerely,

Jill M. Plevinsky

Appendix D

Administered Questionnaires

CHILD DEMOGRAPHIC INFORMATION

Please complete this questionnaire. It should take you 5 minutes. All information is kept confidential and will be used exclusively for research purposes. Make sure you complete all the questions.

1. Age: ____

2. Gender: F____ M____

3. Race/Ethnicity: _____

4. Primary Language: _____

5. Speak more than one language: Yes____ No____

6. Grade level: _____

7. Do you have inflammatory bowel disease? Yes____ No____

8. What is your diagnosis? _____

9. Email address: _____

10. Parent's email address: _____

About Myself

12. Are you currently (check one):

    In school____   Home schooled____   Other____

13. Have you been to Camp Oasis before?

    No____   Yes____

14. Do you know a lot of the other campers?

    No____   A few____   Many____

15. When you are with friends, do you (check one):

    Talk a lot____ Talk sometimes____ Very quiet____

16. Are you excited to be going to Camp Oasis?

    Yes, very!____   A little____   Not really____   Not at all____

17. Do you use the computer a lot?

    Daily____   Weekly____

18. Do you have a Facebook profile?

Yes____   No____

SOCIAL CONNECTEDNESS

Directions: Following are a number of statements that reflect various ways in which we view ourselves. Rate the degree to which you agree or disagree with each statement using the following scale (1=Strongly Disagree and 6=Strongly Agree). Because your answers are describing your honest opinions, there are no right or wrong answers. It is very important that you answer each statement according to your real opinion at this time.

1. I feel comfortable being around strangers.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

2. I feel connected with the world around me.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

3. Even with my friends, there is no sense of brotherhood/sisterhood.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

4. I fit in well in new situations.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

5. I feel close to people.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

6. I feel disconnected from the world around me.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

7.   Even around people I know, I don't feel that I really belong.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

8.   I see people as friendly and approachable.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

9.   I feel like an outsider.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

10. I feel understood by the people I know.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

11. I feel distant from people.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

12. I am able to relate to my peers.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

13. I have little sense of togetherness with my peers.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

14. I find myself actively involved in people's lives.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

15. I catch myself losing a sense of connectedness with society.

Strongly		Mildly	Mildly		Strongly

Disagree	Disagree	Disagree	Agree	Agree	Agree
1	2	3	4	5	6

16. I am able to connect with other people.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

17. I see myself as a loner.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

18. I don't feel related to most people.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

19. My friends feel like family.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

20. I don't feel I participate with anyone of any group.

Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree
1	2	3	4	5	6

SOCIAL SUPPORT QUESTIONNAIRE

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials, their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how <u>satisfied</u> you are with the overall support you have.

If you have had no support for a question, check the words "No one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best you can. All your responses will be kept confidential.

EXAMPLE:

Who do you know whom you can trust with information that could get you in trouble?

No one   1) T.N. (brother)   4) T.N. (father)   7)
            2) L.M. (friend)   5) L.M. (employer)   8)
            3) R.S. (friend)   6)   9)

How satisfied?

6 – very satisfied	5 – fairly satisfied	4- a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

---

1. Whom can you really count on to be dependable when you need help?

No one   1)   4)   7)
            2)   5)   8)
            3)   6)   9)

2. How satisfied?

6 – very satisfied	5 – fairly satisfied	4- a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

3. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No one   1)   4)   7)
            2)   5)   8)
            3)   6)   9)

4. How satisfied?

6 – very satisfied	5 – fairly satisfied	4- a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

5. Who accepts you totally, including both your worst and best points?

No one   1)   4)   7)
            2)   5)   8)
            3)   6)   9)

6. How satisfied?

6 – very satisfied	5 – fairly satisfied	4- a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

7. Whom can you really count on to care about you, regardless of what is happening to you?

No one   1)   4)   7)
            2)   5)   8)
            3)   6)   9)

8. How satisfied?

6 – very satisfied	5 – fairly satisfied	4- a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

9. Whom can you really count on to help you feel better when you are feeling generally down-in-the dumps?

No one   1)   4)   7)
            2)   5)   8)
            3)   6)   9)

10. How satisfied?

6 – very satisfied	5 – fairly satisfied	4- a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

11. Whom can you count on to console you when you are very upset?

No one   1)   4)   7)
           2)   5)   8)
           3)   6)   9)

12. How satisfied?

6 – very   5 – fairly   4- a little   3 – a little   2 – fairly   1 – very
satisfied   satisfied   satisfied   dissatisfied   dissatisfied   dissatisfied

IMPACT-III

A QUALITY OF LIFE QUESTIONNAIRE FOR CHILDREN WITH INFLAMMATORY BOWEL DISEASE

INSTRUCTIONS

Below you will find a questionnaire containing 35 questions for children who have inflammatory bowel disease (Crohn's disease or ulcerative colitis). The questions are about your life with inflammatory bowel disease. Some questions deal with, for example, pains you may suffer from, others are about feelings or worries you may have.

After each question you will see five possible answers. Please mark the area above the answer that best fits your answer.

First an example:

The question is: How afraid are you of tigers?

| | | | X | |
| Not at all afraid | A little afraid | Quite afraid | Afraid | Very much afraid |

So, this person is afraid of tigers.

| | X | | | |
| Not at all afraid | A little afraid | Quite afraid | Afraid | Very much afraid |

This person is a little afraid of tigers.

Please answer all of the questions! If you do not understand a question, ask someone for help.

Good luck with filling in the questionnaire and… many thanks in advance for your efforts!

Question 1:	How much has your stomach been hurting you in the past two weeks?

Not at all	Hardly hurting at all	Hurting somewhat	Hurting quite a bit	Hurting very much

Question 2:	Taking medicines or tablets bothers you.

Not at all	Hardly bothers at all	Bothers somewhat	Bothers quite a bit	Bothers very much

Question 3:	How often has your inflammatory bowel disease prevented you from eating what you want in the past two weeks?

Never	Rarely	Sometimes	Often	Very often

Question 4:	How often have you been worrying about having a flare-up (increase of symptoms) in the last two weeks?

Never	Rarely	Sometimes	Often	Very often

Question 5:	How much does it bother you that you have an illness that does not just go away?

Not at all	Hardly bothers at all	Bothers somewhat	Bothers quite a bit	Bothers very much

Question 6:	How much energy did you have during the past two weeks?

Very much	Quite a bit of energy	Some energy	A little energy	No energy at all

Question 7:   How do you feel about your weight?

| I feel great about my weight | I feel good about my weight | I don't feel good or bad about my weight | I feel bad about my weight | I feel awful about my weight |

Question 8:   How has your inflammatory bowel disease affected your family?

| The effect has been great | The effect has I been good | It has not affected our family | The effect has been bad | The effect has been awful |

Question 9:   How often did you have to miss out on certain things (hobbies, play, parties) because of your inflammatory bowel disease in the past two weeks?

Never   Rarely   Sometimes   Often   Very often

Question 10: How often have you been bothered by diarrhea (loose or frequent bowel movements) in the past two weeks?

Never   Rarely   Sometimes   Often   Very often

Question 11: How often do you worry about health problems you might have in the future?

Never   Rarely   Sometimes   Often   Very often

Question 12: How often do you think it is unfair that you have inflammatory bowel disease?

Never   Rarely   Sometimes   Often   Very often

Question 13: During the past two weeks, were you ever angry that you have inflammatory bowel disease?

Never   Rarely   Sometimes   Often   Very often

Question 14:	Do you think too many rules or limits are placed on you because of your inflammatory bowel disease?

Never	Rarely	Sometimes	Often	Very often

Question 15:	How do you feel about the way you look?

I think I look great	I think I look good	I don't think I look good or bad	I think I look bad	I think I look awful

Question 16:	Are you embarrassed because of your bowel condition?

Not at all	Hardly embarrassed at all	Embarassed somewhat	Embarassed quite a bit	Embarassed very much

Question 17:	Did you have fun during the past two weeks?

Very often	Often	Sometimes	Rarely	Never

Question 18:	Is it harder to make friends because of your inflammatory bowel disease?

Not at all harder	A little harder	Quite a bit harder	Much harder	Very much harder

Question 19:	How often do you worry about your stool (bowel movement) containing blood?

Never	Rarely	Sometimes	Often	Very often

Question 20:	Are you worried you cannot go out on a date or have a boyfriend or girlfriend because of your inflammatory bowel disease?

Not at all worried	Hardly worried at all	Worried somewhat	Worried quite a bit	Worried very much

Question 21:	How often did you feel sick to your stomach in the past two weeks?

Never	Rarely	Sometimes	Often	Very often

Question 22:	How do you feel about the tests you have to go through?

I do not mind them at all	I mind them a tiny bit	I mind them a little	I mind them a lot	I hate them

Question 23:	Do other children bully you or leave you out of things because of your inflammatory bowel disease or its treatment?

Never	Rarely	Sometimes	Often	Very often

Question 24:	How often do you worry about having an operation?

Never	Rarely	Sometimes	Often	Very often

Question 25:	In the past two weeks how often were you afraid you may have an accident or not get to the toilet in time?

Never	Rarely	Sometimes	Often	Very often

Question 26:	Do you try to keep your inflammatory bowel disease a secret from other people?

No, I do not try at all	I don't try much	I try a little	I try hard	Yes, I try very hard

Question 27:	Does your inflammatory bowel disease make it difficult to travel or go on a holiday?

No, not difficult	A little difficult	Quite difficult	Very difficult	Yes, extremely difficult

Question 28:	How did you feel during the past two weeks?

Great	Good	Not good or bad	Bad	Awful

Question 29:	Are you happy with your life?

Yes, very happy	Happy	Not happy or unhappy	Unhappy	Very unhappy

Question 30:	Do you feel there is someone you can talk to about your inflammatory bowel disease?

Always	Often	Sometimes	Rarely	Never

Question 31:	How often did you have to pass gas in the past two weeks?

Never	Rarely	Sometimes	Often	Very often

Question 32:	How tired have you felt in the past two weeks?

Not at all	A little tired	Quite tired	Tired	Very tired

Question 33:	How do you feel about your height?

I feel great about my height	I feel good about my height	I don't feel good or bad about my height	I feel bad about my height	I feel awful about my height

Question 34:	Does your inflammatory bowel disease get in the way of playing sports the way you would like to?

Never	Rarely	Sometimes	Often	Very often

Question 35: In the past two weeks how often were you able to go to school? (If you are in the middle of a school break or the summer holidays, answer as if school was on)

Always   Most days   Half the days   A few days   Never

INTERNET SOCIALIZATION AND FACEBOOK USE

This questionnaire will ask about your use of the internet for socializing.

1. Do you have reliable internet access? ○ Yes ○ No

2. How often do you use the internet, including email? _____ hours per week

3. Do you visit social networking websites like Facebook or MySpace? ○ Yes ○ No

4. Compared to other kids my age, I feel that I use social networking sites:
   ○ More than my peers   ○ About the same as my peers   ○ Less than my peers

5. Do you have a profile on Facebook? ○ Yes ○ No

IF YOU MARKED "No," PLEASE GO TO QUESTION 15. IF YOU MARKED "Yes," KEEP GOING → → →

6. How much time do you spend on social networking site(s)? _____ hours per week.

7. How often do you use social networking sites to (Check all that apply):

		Never	Rarely	Sometimes	Fairly Often	Often
7a	Keep in touch with my friends from Camp Oasis.					
7b	Learn more about other people I went to Camp Oasis with.					
7c	Check out someone I met socially at Camp Oasis.					
7d	Make positive comments to people.					
7e	Browse profiles of people I don't know.					
7f	Make negative comments to people.					
7g	Look at my friends' profiles.					
7h	Threaten or embarrass someone.					
7i	Make positive comments about other people.					
7j	Learn more about other people living near me with					

	inflammatory bowel disease.					
7k	Meet new people with inflammatory bowel disease.					

7l	To show disgust or dislike of another person.					
7 m	Flirt/show romantic interest.					
7n	Make negative comments about other people.					
7o	Join groups or like pages that have to do with inflammatory bowel disease.					
7p	Coordinate plans with friends.					
7q	Read comments on profile page/wall or on other material I have posted.					
7r	Seek information about inflammatory bowel disease.					
7s	Search for other patients with inflammatory bowel disease.					
7t	Ask other patients about their experiences with inflammatory bowel disease.					
7	Other: _____ _____					

8. When I'm not feeling well, I use social networking sites _____ when I'm feeling healthy.
    ○ More than   ○ About the same   ○ Less than

9. When I have to miss school, I use social networking sites _____ when I don't miss school.
    ○ More than   ○ About the same   ○ Less than

10. Social networking sites are part of my everyday activity:
    ○ Strongly Disagree ○ Disagree   ○ Neutral   ○ Agree   ○ Strongly Agree

11. After meeting someone through Facebook, I have communicated with this person through e-mail, text message, telephone call, and/or face-to-face:
    o   Yes
    o   No. I've met new people, but we haven't met in real life or communicated via text messaging or phone calls.
    o   No. I have never met anyone new on a social networking site.

12. On Facebook, the majority of my friends are people:
- o   I know in real life.
- o   I don't know in real life.

13. On Facebook, the majority of my friends are people:
- o   With inflammatory bowel disease.
- o   Without inflammatory bowel disease.

14. Someone else has used Facebook to (check all that apply):

		Never	Rarely	Sometimes	Fairly Often	Often
13a	Make positive comments TO me.					
13b	Make positive comments ABOUT me.					
13c	Make negative comments TO me.					
13d	Make negative comments ABOUT me.					
13e	Threaten or embarrass me for other people to see.					
13f	Bother or harass me online.					
13g	Ask me questions about inflammatory bowel disease.					
13h	Ask me questions about my personal experiences with inflammatory bowel disease.					

15. a. Does your parent or guardian have rules or limits about your Facebook use?
  ○ Yes   ○ No

  b. If yes, what rules do they have? (select all that apply)
- o   Time limit (only use Facebook for so many hours or minutes)
- o   "Curfew" (do not use Facebook after a certain time of night)
- o   Use Facebook for fun only after homework is done
- o   Location (only use Facebook in a common area in the home)
- o   Allow your parent access to any accounts or profiles
- o   Parental internet controls/"Net nannies"
- o   Other (please list):

  _____

  _____

Please skip to Question 17.

16. I do not use Facebook because (mark all that apply):
- o My friends don't use it.
- o I don't know anyone with whom I'd communicate.
- o I don't have reliable access to the internet and/or the sites.
- o I am not allowed.
- o I'm too busy.
- o I don't like social networking sites.
- o I don't think social networking sites are safe.
- o I want to be different from the other kids who use them.
- o Other:

  _____

  ____

17. My previous experience with Facebook can be described by the following statement(s) (mark all that apply):
- o I have never used Facebook before.
- o I have used Facebook in the past, but did not have my own profile.
- o I used to have a profile on Facebook, but I deleted it.
- o My friend made me a profile on Facebook that I do not use.
- o I currently have a profile on Facebook, but I do not use it anymore.

STOP! Please let your study staff member know you are done to continue to the next section.

18. How many friends do you have on Facebook?

Number_____

19. How many groups and/or fan pages have you joined on your social networking sites?

Number_____

20. How many IBD-specific groups and/or fan pages have you joined on Facebook?

Number_____

21. I am a member of groups of the following categories: (list groups)

22. If you are member of a group for inflammatory bowel disease:
   a. Why do you choose to visit this group?
- o It provides a lot of answers to my questions about the illness.
- o Other people with this illness understand how I feel.
- o The others on the site encourage me when times are tough.
- o Other:

  _____

  _____.

b. When I am on the IBD group page, I (check all that apply):
- o read other peoples' comments and discussions
- o rarely post information and/or my thoughts.
- o sometimes post information and/or my thoughts.
- o fairly often post information and/or my thoughts.
- o often post information and/or my thoughts.

c. If **No**, I would be interested in joining a group related to a different chronic illness? ○ Yes ○ No

d. If Yes, what illness? _____

23. I would be interested in joining a social-networking group or website just for adolescents with IBD:

○ Strongly Disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly Agree

24. I would prefer an IBD-related social networking website in the following format, please check all that apply:
- o A stand-alone website with its own web address
- o A group page on MySpace
- o A fan page or group page on Facebook
- o An application on Facebook
- o An application I could download to my cell phone or iPod
- o Other:

_____
_____

25. I would like an IBD social networking website to feature the following:

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
35a	Medical information about IBD, medicines, surgeries, etc.					
35b	Advice about dealing with IBD					
35c	Connect with a helpful older teen or young adult with IBD					
35d	Find a person to date					
35e	Discussion boards					
35f	A profile I could personalize about myself					
35g	IBD-related games and puzzles.					

35h	Chance to communicate with doctors and/or nurses.					
35i	News about upcoming IBD activities (ex.: CCFA walk)					
35j	Chat room for teenage members					
35k	Video chat with other teens with IBD					
35l	Area to post pictures and/or video					
35m	Ways to connect with local teens who have IBD					
35n	Ways to connect with non-local teens who have IBD					
35o	Quizzes about IBD					
35p	Material that is not related to IBD					
35q	Helpful links					

Appendix E

Continuing Camp Oasis Code of Conduct

<u>CODE OF CONDUCT & FACEBOOK SAFETY GUIDELINES</u>
Continuing Camp Oasis: Adolescent Utilization of Facebook for Social
Support

I agree to follow this code of conduct and respect these guidelines while I am using the Continuing Camp Oasis Facebook group:

- *All members of the Facebook group are encouraged to post personal stories, questions, videos, articles, links, etc. I will help this happen by not doing anything to disrupt or discourage another's thoughts.*
- *In an attempt to make everyone feel comfortable in the Facebook group, I will not use profanity and/or discriminatory language. In addition, I will not use language that purposefully offends another member of the Facebook group.*
- *Use responsible and appropriate behavior as well as appropriate words in your comments, posts, photos, and videos shared on the Facebook group wall. Be respectful so others don't feel insulted or offended. Keep in mind that some of the participants might be younger than you. If you don't like what someone does or says, please tell or email the administrator of the Facebook group or Jill Plevinsky at jillplev@gmail.com. If you are not sure if something will offend someone, first ask yourself: Would I like if someone did this to me? Everything that is posted on the Facebook group will be monitored to make sure that all participants are using responsible and appropriate language and behavior.*
- *Ask questions if there are things that you do not understand.*
- *If you think that there are new rules that need to be added to this list, please send them to us.*
- *Never enter your address or phone number on Facebook. This is important in order to keep your privacy and security.*
- *Never agree to meet anyone in person who you meet over the Internet. It is impossible to know who you are really talking to. If someone encourages you to meet with them, tell the group administrator or your parent/guardian.*
- *If you receive messages that are mean or make you feel uncomfortable, tell the group administrator. It is not your fault if you get a message of this kind and you have no responsibility to answer. If in doubt, check with an adult.*

- *Remember that information posted on the Facebook group can be incorrect, misleading or inappropriate.*
- *When using the Facebook group at home, make sure your parents or guardians are aware of your activities.*

_____   _____

Date   Signature of Child/Adolescent Participant

Appendix F

Participant Debriefing

<u>DEBRIEFING FORM</u>
Continuing Camp Oasis: Adolescent Utilization of Facebook for Social Support

PURPOSE
The purpose of this study as outlined in both the Consent and Assent Form, truly was to evaluate the efficacy of virtual online social support, particularly, the use of Facebook groups as support mechanisms for adolescents with inflammatory bowel disease (IBD). The researcher hypothesizes that in an increasingly virtual world, online support, while very different in nature from in-person social support, can still produce similar adaptive effects in a community of adolescents with the same chronic illness. The researcher anticipates that the increased positive outcomes resulting from spending a week at Camp Oasis will be at least maintained, if not intensified by the patients' participation in an IBD-specific Facebook group.

BACKGROUND
In 2004, a group of researchers made of mental health professionals, registered nurses, and physicians collaborated on a study to measure the effectiveness of Camp Oasis on health-related quality of life in adolescents with inflammatory bowel disease and they found that overall health-related quality of life improved after attending. (Shepanski, Hurd, Culton, Markowitz, Mamula, and Baldassano, 2005). In addition, it has been well-researched that in patients with inflammatory bowel disease, social support contributes to increase health-related quality of life which has been associated with other positive outcomes including treatment adherence, self-esteem, self-efficacy, and even better health outcomes (Greenley, Hommel, Nebel, Raboin, Li, Simpson, and Mackner, 2010). The problem is, not every child has access to Camp Oasis, or a local clinic that holds supportive events for patients. The Internet is a great resource, and is becoming more and more prevalent as a source of identity (Boyd, 2008) and health information (Gray, Klein, Noyce, Sesselberg, and Cantrill, 2005). If it is proven equally as effective as in-person social support, clinicians and web developers can get to work on a safe and secure online environment for adolescent patients that will foster a better health-related quality of life, and hopefully better health outcomes overall as well.

CONFIEDENTIALITY
The Facebook group was only accessible to the other members of the group and staff participating in the study. All information gathered from interviews, questionnaires, and the Facebook group was kept private. A unique ID was assigned to each participant that was used instead of contact information to identify the participant. Once the study has ended, the Facebook group will be deleted so as to protect the users' privacy. In the debriefing process, users will be

referred to other successful online support mechanisms within the Facebook platform and beyond, and also encouraged to start their own group independent of the present study. The results from this study will not be placed in the participant's medical record, and no other related parties will learn of the results either.

FINAL REPORT

If you are interested in obtaining a copy of the final report of this study, contact the primary investigator, Jill Plevinsky at ███████████████ or ██████████ .

CONTACT

If you have any questions regarding this study, its purpose or procedures, please feel free to contact the primary investigator Jill Plevinsky at ███████████████ or ██████████ or the Tufts University Institutional Review Board at (617) 627-3417. Thank you!

FOR FURTHER READING

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Table 1

Participant Mean of Social Connectedness, Social Support Number, and Social Support Satisfaction Scores

	Social connectedness	Social support number	Social support satisfaction
Pre Camp Oasis	62.52	3.81	5.13
Post Camp Oasis	63.35	3.56	4.64
Post Facebook	67.76	3.97	4.73

Table 2

Participant Means of IMPACT-III Scores

	Pre Camp Oasis	Post Camp Oasis	Post Facebook
HRQoL	128.8	136.89	132.1
QOLBS	26.35	27.34	26.75
QOLSS	10.90	11.63	11.05
QOLEF	23.15	25.47	26.05
QOLSF	48.15	49.58	45.67
QOLBI	9.2	10.47	10.38
QOLTXI	11.2	11.89	11.67

Table 3

Social Support and IMPACT-III Quality of Life Correlations

Social Support	Pre Camp Oasis (T1)	Post Camp Oasis (T2)	Post Facebook (T3)
QOL	---	.519* (T2)	.445* (T1) .508* (T2)
QOLSF	---	.467* (T2)	.495* (T1) .588** (T2) .463* (T3)
QOLBI	---	.525* (T1) .683** (T2) .704** (T3)	.447* (T1) .513* (T2)
QOLTXI	.462* (T3)	.516* (T1) .461* (T3)	---
QOLSS	---	.611** (T2)	---

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).
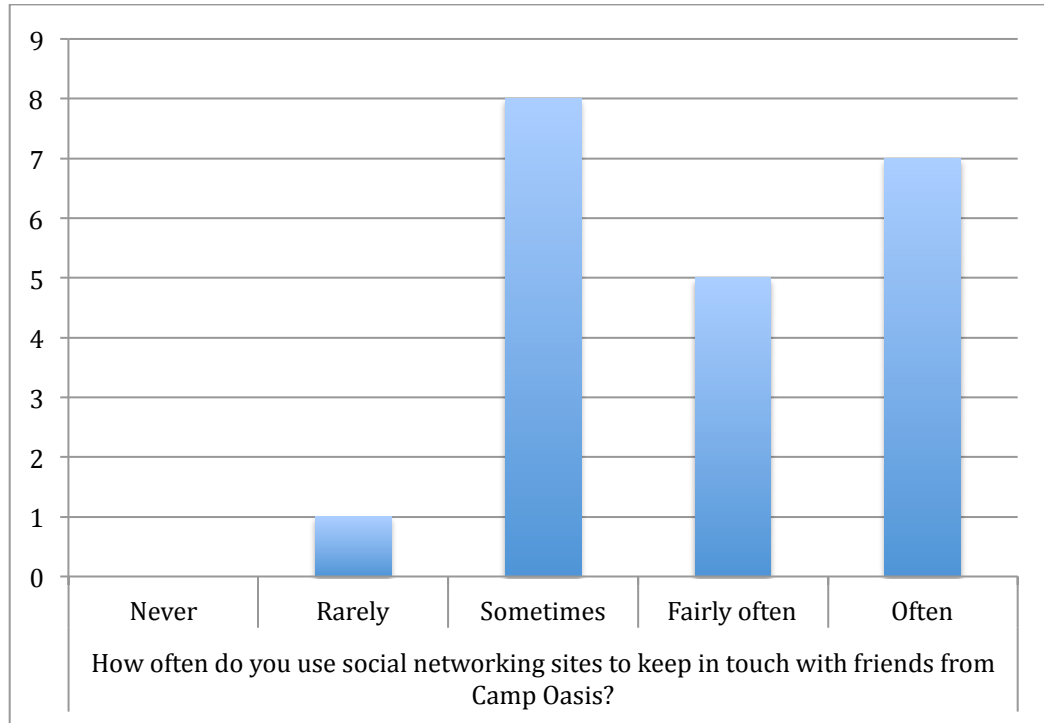
Figure 1. This chart depicts how often participants use social networking sites to keep in touch with their friends from Camp Oasis.
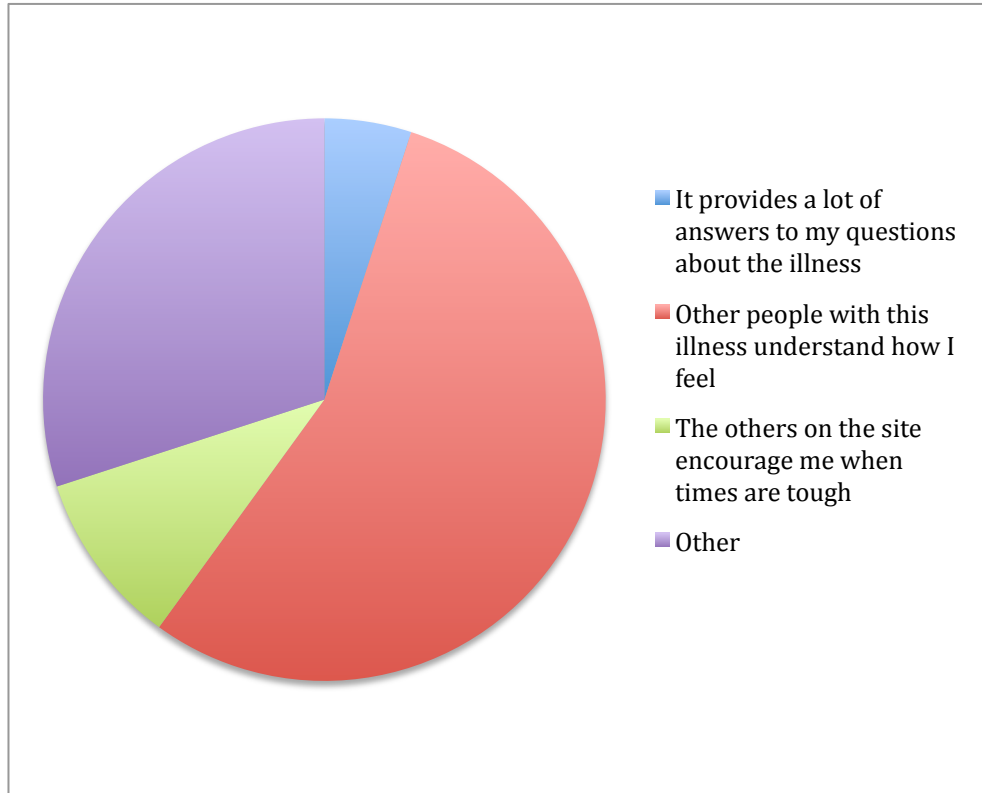
Figure 2. This chart shows the reasons participants gave for membership of an IBD-specific Facebook group. Answers to this question provide implications for the creation of social support mechanisms for adolescents with IBD.
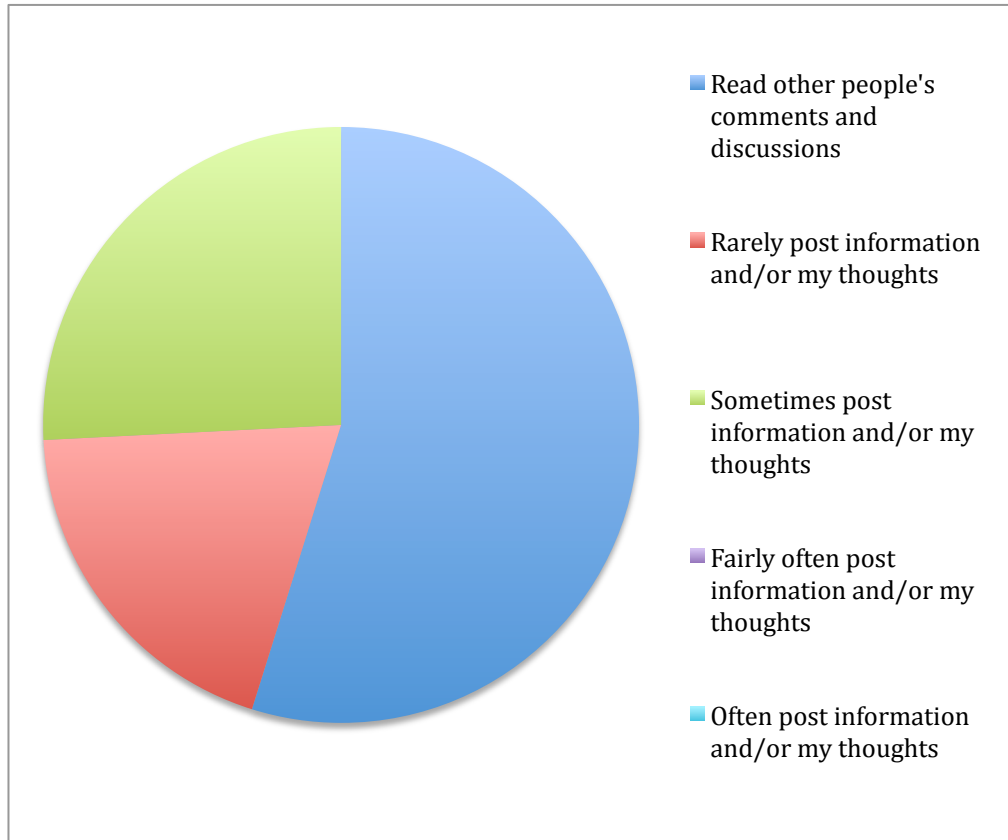
Figure 3. This figure shows the types of activity that participants reported taking part in within IBD-specific groups and pages on Facebook.
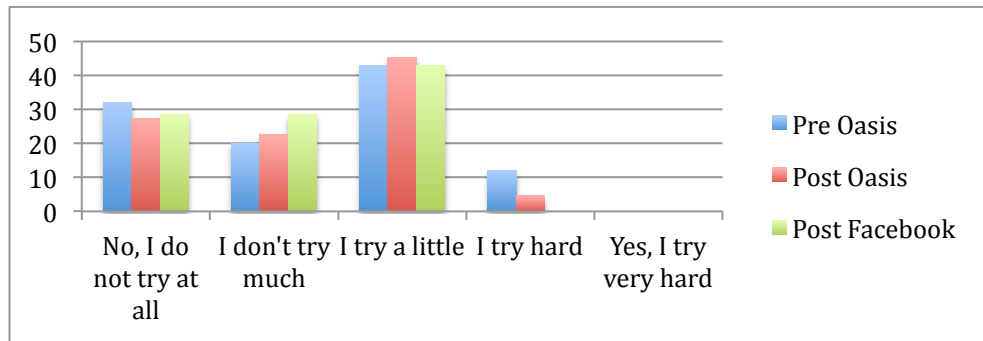
Figure 4. This chart displays how the answer to the IMPACT-III question of how hard the participants try to keep their illness a secret changed across the three measurement points.
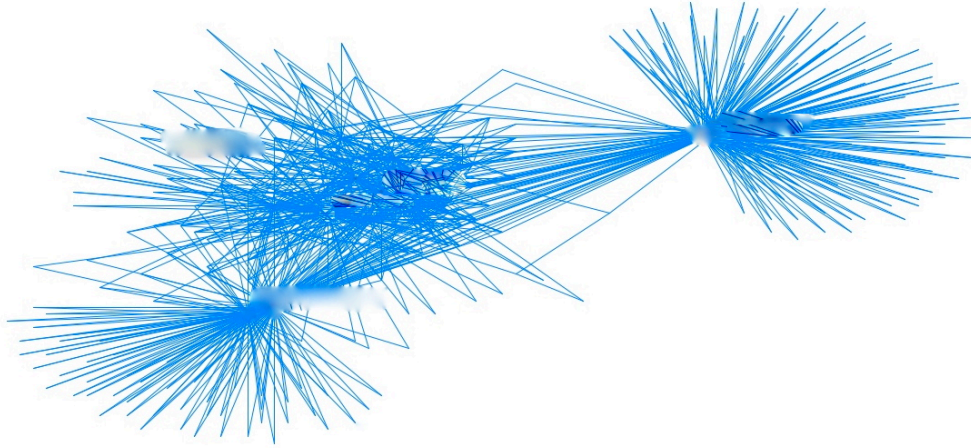
Figure 5. A visualization of the network between participants in Continuing

Camp Oasis.

From the figure, three major clusters can be identified, one of which (upper left-

hand corner) is very well networked given the interconnectedness of the lines.
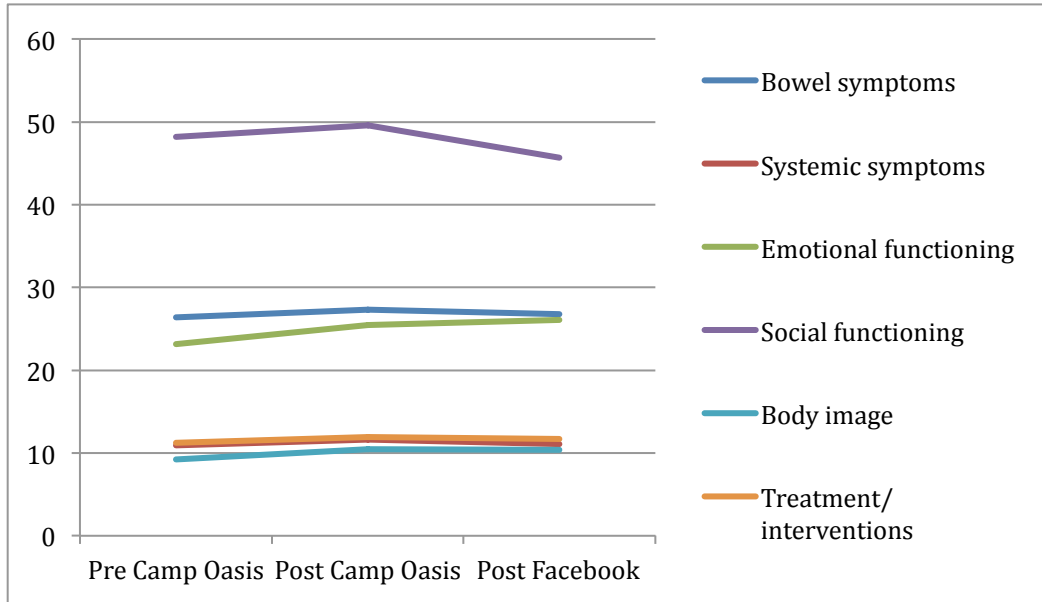
Figure 6. A line chart of all of the constructs from the IMPACT-III health-related quality of life questionnaire over time. This figure corresponds with the measurements from Table 2.

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