

HEALTH-RELATED QUALITY OF LIFE OUTCOMES OF PARTICIPANTS IN A  
MONTANA-SPECIFIC, ONLINE SUPPORT COMMUNITY FOR PEOPLE IN  
MONTANA WITH INFLAMMATORY BOWEL DISEASE

by

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## TABLE OF CONTENTS

1. INTRODUCTION .....	1
Problem .....	5
Purpose .....	6
Research Questions .....	6
Significance of the Study .....	7
Literature Review/Theoretical Framework .....	8
Chronic Illness Theories .....	10
Social Support Theory .....	11
Social Learning Theory.....	12
Research Design .....	15
Quantitative Phase .....	16
Qualitative Phase .....	17
Definitions .....	19
Limitations of the study.....	21
Delimitations of the study .....	21
Assumptions .....	22
Chapter Summary.....	22
2. LITERATURE REVIEW .....	24
Chronic Disease.....	25
Psychological and Psychosocial Issues.....	26
Chronic Illness Theories .....	28
Health-Related Quality of Life and Chronic Disease.....	30
Impacts on Health-Related Quality of Life.....	33
Health-Related Quality of Life Influences.....	34
Social Support.....	34
Implications of Social Support.....	37
Social Networks .....	37
Peer Support.....	39
Support Groups .....	40
Illness Knowledge.....	44
Information Sources.....	46
Peer Information Exchange.....	49
Adult Learning Theories .....	49
Transformative Learning Theories .....	51
Implications of Illness Knowledge .....	53
Learning Communities.....	55
The Expert Patient.....	56

## TABLE OF CONTENTS - CONTINUED

Illness Representations.....	57
Coping Strategies .....	59
The Internet and Chronic Disease .....	61
Social Media .....	62
Social Networks .....	63
Internet and Health.....	65
Chronic Disease and Internet Use.....	67
Online Disease-Related Information.....	68
Online Health Communities .....	69
Online Social Support.....	74
Misinformation .....	76
Inflammatory Bowel Disease .....	77
Physical Aspects of Inflammatory Bowel Disease .....	79
Psychological Factors of Inflammatory Bowel Disease .....	81
Inflammatory Bowel Disease and Health-Related Quality of Life.....	83
Social Support and Inflammatory Bowel Disease .....	85
Illness Knowledge and Inflammatory Bowel Disease .....	87
Illness Representations of Inflammatory Bowel Disease .....	88
Coping Strategies in Inflammatory Bowel Disease .....	89
The Internet and Inflammatory Bowel Disease .....	90
Online Inflammatory Bowel Disease-Related Knowledge .....	90
Online Social Support for Inflammatory Bowel Disease .....	92
Inflammatory Bowel Disease in Montana.....	93
Pilot Studies .....	95
Chapter Summary.....	98
 3. METHODOLOGY .....	 100
Background and Purpose.....	100
Overview of the MontanasGotGuts Website .....	101
Researcher Positionality and Reflexivity.....	102
Rationale for Descriptive Study.....	102
Quantitative Phase.....	103
Participants .....	103
Design and Procedure .....	105
Instrument .....	106
Data Collection and Analysis .....	109
Qualitative Phase.....	110
Participants .....	110
Design and Procedure .....	110
Interview Protocols .....	111
Data Collection and Analysis .....	112

## TABLE OF CONTENTS - CONTINUED

Trustworthiness .....	113
Chapter Summary .....	114
4. RESULTS .....	115
Introduction .....	115
Quantitative Data .....	116
Demographic Factors .....	116
Website Analytics .....	118
Internet Usage and Usefulness .....	120
Community Participation Experiences .....	122
Summary of Quantitative Data .....	124
Qualitative Data .....	125
Theme 1: Participants Expressed a Need to Meet Others with IBD .....	126
Subtheme 1: Participants Valued Knowing That Others With IBD Live Nearby .....	126
Subtheme 2: Participants Valued Finding Others Who Share Similar Demographics .....	127
Subtheme 3: Participants Valued the Opportunity to Meet Others in Person .....	130
Theme 2: Participants Demonstrated Low Active Participation Levels .....	131
Subtheme 1: Participants Would Actively Participate More if There Were More Contributions by Others .....	131
Subtheme 2: Participants Suggested Personality Traits as a Barrier to Participation .....	132
Subtheme 3: Participants Suggested Time as a Barrier to Active Participation .....	133
Theme 3: Participants Valued the Community as a Source of IBD-Related Information .....	134
Subtheme 1: Participants Suggested That Information Most Helpful Aspect of the Community .....	135
Subtheme 2: Participants Suggested That Information More Valuable When it Comes From Others With IBD .....	138
Subtheme 3: Participants Expressed a Need to Share Information and Experiences With Others .....	139
Subtheme 4: Participants Exhibited a High Level of Lurking Behavior .....	140
Theme 4: Participants Valued the Community as a Source of Social Support .....	141
Subtheme 1: The Concept of “Support” Meant Something Different to Many Participants .....	141

## TABLE OF CONTENTS – CONTINUED

Subtheme 2: The Term “Support” Sometimes Garnered Negative Connotations From Participants .....	143
Subtheme 3: Participants Demonstrated That the Potential for Support Can Be as or More Beneficial Than Actual, Active Support ....	144
Subtheme 4: Participants Valued Feedback Within the Community, Whether Active or Passive.....	145
Outliers of Significance .....	146
Chapter Summary .....	148
5. CONCLUSIONS.....	149
Introduction .....	149
Overview of the Study.....	149
Research Questions Answered .....	150
Research Question 1 .....	150
Research Question 2 .....	152
Research Question 3 .....	153
Comparison to the Literature.....	154
Study Conceptual Model Revisited .....	157
Recommendations .....	159
The Researcher.....	159
National IBD Community.....	161
Those with IBD.....	162
IBD Physicians and Healthcare Professionals .....	162
Online Health Community Administrators.....	163
Limitations of the Study.....	164
Suggestions for Further Research.....	165
Chapter Summary .....	166
REFERENCES CITED.....	167
APPENDICES .....	185
APPENDIX A: Overview of Popular Online IBD Support Websites.....	186
APPENDIX B: MontanasGotGuts.org Website Screenshots.....	188
APPENDIX C: Participant Recruitment Email.....	190
APPENDIX D: MontanasGotGuts.org Participant Survey .....	192
APPENDIX E: MontanasGotGuts.org Participant Interview Questions .....	204
APPENDIX F: MontanasGotGuts.org Poster .....	206

## LIST OF TABLES

Table	Page
1. Table of Specifications .....	107
2. Participant Demographics (in alphabetical order by first name pseudonym) .....	117
3. MontanasGotGuts.org Website Traffic by Month: October 1, 2012 – September 30, 2013.....	119
4. MontanasGotGuts.org Website Activity per Page Content: October 1, 2012 – September 30, 2013.....	119
5. Usefulness of Website Areas (in order of usefulness combining extremely and very useful) .....	121
6. Online Community as Compared to Other Support and Information Resources.....	122
7. Participant Responses to Questions Regarding Social Support (in descending order of highest agreement) .....	123
8. Participant Responses to Questions Regarding Illness Knowledge (in descending order of highest agreement) .....	124



LIST OF FIGURES

Figure	Page
1. Conceptual Model for the Study .....	9
2. Revised Conceptual Model for the Study .....	158

## ABSTRACT

Research shows that access to social support can help mitigate the negative psychological effects of chronic illness, and positively influence health outcomes, ultimately improving the health-related quality of life (HRQOL) of those affected. However, many with inflammatory bowel disease (IBD) in Montana may lack access to social support and illness-related knowledge needed to manage their disease successfully. If a viable, accessible, and beneficial opportunity were available, it would be crucial to have the endorsement of local physicians. The problem addressed in this study was that those serving individuals in Montana with IBD need to know how individuals participating in a Montana-specific, online support community for those in Montana with IBD assess and describe their experiences within the community, and how they report that their experiences have affected their HRQOL in the areas of social support and illness knowledge. Three research questions were posed: How do participants assess and describe their experiences within the online community; how have their experiences impacted their HRQOL as exhibited through impacts on social support; and, how have their experiences impacted their HRQOL as exhibited through impacts on illness knowledge? Ten participants were recruited from the membership of the online community, MontanasGotGuts.org. A 20-item, self-report survey instrument was initially used to obtain demographic data, website usage data, and data on participants' experiences. Next, qualitative research methods, using semi-structured interviews, were conducted to collect more insightful, descriptive data. Study findings consisted of four major themes with 14 subthemes that illustrated how the participants experienced the online community. The major themes included: participants expressed a need to meet others with IBD; participants reported low active participation levels; participants valued the community as a source of IBD-related information; and, participants valued the community as a source of social support. Recommendations were made to the researcher, the national IBD community, those with IBD and their physicians, and other online health community administrators.

## CHAPTER 1

## INTRODUCTION

The use of online social networks has increased tremendously over the past ten years. Today there are over 600 million active Facebook users and counting. In August 2010, 43% of all Americans had a Facebook account (Fox, 2010). In general, online social network use has quadrupled from 2005 to 2009 (O'Grady, et al., 2008; Fox, 2010). Online social network use by those with chronic illnesses and conditions is also on the rise (Fox, 2010). People with chronic illness participate in online social networks for many of the same reasons they attend face-to-face support groups, namely to access much needed social support and disease-related knowledge from those who share the same experiences (Colineau & Paris, 2010; Im, Chee, Lim, & Liu, 2007; G. J. Johnson & Ambrose, 2006; Miller, 2010; Sarasohn-Kahn, 2008; Shirky, 2008; C. F. van Uden-Kraan, Drossaert, & Taal, 2008). Online social networks offer the flexibility and access that offline support groups just cannot match. With online communities, patients control when and how much they participate, whereas offline groups dictate a specific time and place for meetings (Im et al., 2007; LaCoursiere, 2001; Quin, Stams, Phelps, Boley, & Hazelrigg, 2010; C. F. Sullivan, 2003; CF van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008; Winzelberg et al., 2003). But, most importantly, online social networks can provide a resource for support and disease-related knowledge for those who may feel isolated, whether geographically, physically or socially, and lack access to others with the same illness (Im et al., 2007; P. K. H. Mo & Coulson, 2010; C. F. van

Uden-Kraan et al., 2008). Many studies show a direct link between social support experienced online and positive psychosocial and emotional outcomes reported by participants. This, in turn, can lead to a greater health-related quality of life for those participants, which is a crucial component of successful disease management (Barrera, Glasgow, McKay, Boles, & Feil, 2002; Seckin, 2009; Shigaki et al., 2008).

Inflammatory bowel disease (IBD) is the term used to describe two similar, yet distinct, inflammatory disorders of the gastrointestinal tract, Crohn's disease and ulcerative colitis (Blank & Switzer, 2006; Crohn's and Colitis Foundation of America, 2011; Hall, Rubin, Dougall, Hungin, & Neely, 2005; Swickert, 2002; Verma, Tsai, & Giaffer, 2001). An estimated 1.4 million Americans have been diagnosed with IBD, with ulcerative colitis outnumbering Crohn's disease about two to one. Symptoms include abdominal pain, weight loss, rectal bleeding, diarrhea, urgency, nausea, and fatigue. Whereas ulcerative colitis is confined to the colon, the inflammatory effects of the Crohn's disease can become systemic and involve the skin, eyes, joints, and liver (Crohn's and Colitis Foundation of America, 2011). Although several powerful medications are available to help stem the inflammation and reduce symptoms, many require multiple surgeries to remove affected areas. There is currently no cure for IBD (Crohn's and Colitis Foundation of America, 2011). In lieu of a cure, the goal in the medical management of IBD is to induce and maintain clinical remission, reduce inflammation, and control nutritional deficiencies and symptoms (Blank & Switzer, 2006; Crohn's and Colitis Foundation of America, 2011; Hall et al., 2005). Inflammatory bowel disease is characterized by unpredictable periods of relapse and remission, and can have

serious physical, social and emotional repercussions that may result in decreased in quality of life (Blank & Switzer, 2006; F. Casellas et al., 2005; Hall et al., 2005; Oliveira et al., 2007; Verma et al., 2001). Those with IBD tend to be more private and secretive about their illness, due in part to the embarrassing nature of the disease, but also because IBD is not as well known as other chronic illnesses (Lonardi, 2007). Further, many with IBD are reluctant to discuss their fears and concerns regarding their disease with family, friends or even their physician (Robertson, Ray, Diamond, & Edwards, 1989).

Although there are no solid numbers as to the prevalence of IBD in Montana, extrapolating from the national numbers and anecdotal estimates from one Montana gastroenterologist would suggest that there may be as many as 5000 people in Montana living with IBD (Molodecky et al., 2012; Shaneyfelt, 2013). The added burden of living in a lesser-populated area such as Montana, where there is less opportunity to meet others with IBD, may increase feelings of isolation. To compound this isolation, the Crohn's and Colitis Foundation of America (CCFA), the preeminent source of support, education and research for those with IBD, has very little presence in Montana due to budget constraints and the relatively small population of people with IBD in Montana. Consequently, people in Montana with IBD may not have adequate access to social support opportunities and illness-related knowledge necessary to successfully manage their disease.

This researcher has conducted two qualitative studies with individuals with IBD in Montana. The goal of each study was to explore the experiences of individuals with IBD in Montana (Nehasil, 2009a, 2009b). The primary findings from interviews with a

total of 16 individuals in the two studies revealed that they had little or no contact with other people who had IBD. Additionally, every participant reported that their main avenue for support regarding their disease was their family. However, many went further to say that most often their family and friends do not or cannot understand their condition, and, at times, they feel they are a burden to their family and friends.

All 16 participants reported the Internet as their number one source for IBD-specific information. Although many reported that it was sometimes difficult to find information online and much of what they found was confusing, as one participant stated, “It’s the only game in town.” In addition, all expressed a strong desire to meet and share their experiences with others who have IBD, and a need for a local patient network to help those with IBD find peers within their own community. One especially poignant comment summed up the Montana IBD experience very well: “Location is becoming a minor part of it. There’s still the problem of finding and reaching people.”

Many people with IBD who live in Montana report visiting some of the many online IBD forums and communities that already exist, but with mixed result (Nehasil, 2009a, 2009b). Although many of the more popular websites are very large and have thousands of members, many describe an impersonal atmosphere. One of the criticisms of these large, world-wide communities is that while there are many more people with whom one can potentially share information, and a high amount of information available, there is little chance of having the opportunity to meet any other members in person. As these forums are open to international membership, someone in Manhattan, Montana might be conversing with someone in Manhattan, New York. And, while they might

share many of the same experiences common to those with IBD, there are many issues, frustrations, and challenges that are unique to living in Montana that someone in New York, or Australia, may not be able to comprehend. Furthermore, many of the larger forums do not allow members to identify themselves by location; so many times the whereabouts of a person are unknown. Appendix A presents an overview of eight of the more popular online IBD support websites. While many tout impressive numbers of members and high activity levels, the ability to differentiate members by location is a disadvantage to some sites.

As a result of these studies, this researcher designed and developed an online social support community, MontanasGotGuts (<http://montanastgotguts.org>) for those with IBD in Montana (see Appendix B). The goals of the website are to provide a platform through which those in Montana with IBD can receive and provide social support to others, and to provide an impetus to build an IBD network in Montana whereby those with IBD can find peers within their community. The website has a framework similar to that of Facebook, with member profiles, an activity wall, status updates, live chatting, private messaging, and discussion forums. One key feature of this community is an interactive GoogleMap™ that displays the location of each member, allowing members to visibly find others that may live in their city or even in the neighborhood.

### Problem

The problem addressed in this study was that those serving individuals in Montana with IBD need to know how individuals participating in a Montana-specific,

online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge.

### Purpose

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge.

### Research Questions

Health-related quality of life is a term used to explain how illness affects an individual when clinical indicators alone are insufficient (Blank & Switzer, 2006). It involves a person's emotional, social and physical well-being and his or her ability to perform tasks of every day living (Donald, 2001; Pulman, 2010; Shaneyfelt, 2013; Verma et al., 2001). Health-related quality of life is increasingly becoming a major factor in treatment and illness management plans. (Ferrans, Wilbur, Zerwic, & Larson, 2005; Hall et al., 2005).

This study posed the following research questions regarding participation in a Montana-specific, online support community for people in Montana with IBD:



1. How do participants assess and describe their experiences within the online community?
2. How have their experiences impacted their HRQOL as exhibited through impacts on social support?
3. How have their experiences impacted their HRQOL as exhibited through impacts on illness knowledge?

### Significance of the Study

Research shows that access to social support can help mitigate the negative psychological effects of chronic illness, and positively influence health outcomes, ultimately improving the health-related quality of life of those affected (Colineau & Paris, 2010; Moskovitz, Maunder, Cohen, McLeod, & MacRae, 2000; Shigaki et al., 2008). Additionally, interaction with others with the same chronic illness can provide opportunities to gain much needed illness-related knowledge (C. Campbell, 2001; Krause, 2003). However, many with IBD in Montana lack access to social support and illness-related knowledge needed to manage their disease successfully. Studies also suggest that patients will more likely participate in a disease-specific support or education activity when specifically recommended by their physician (Eakin & Strycker, 2001; Guidry, Aday, Zhang, & Winn, 1997; Sherman et al., 2008). The lack of opportunities available in Montana, however, makes this somewhat a mute point. If a viable, accessible, and beneficial opportunity were available, it would be crucial to have the endorsement of local physicians. This study will provide Montana physicians and other

health professionals' data demonstrating the viability of a Montana-specific, online support community for those in Montana with IBD, and potential benefits to their patients' overall quality of life.

### Literature Review/Theoretical Framework

A few decades ago, clinical and laboratory measurements were generally the sole indicators of illness status and treatment outcomes. In recent years, however, clinicians and researchers have begun to view the patient's own perceptions of his or her health as important factors in research and clinical care. Central to this movement was this question: Given the same disease with similar clinical and biological indicators, why do some patients successfully adapt to their illness, even thrive, while others continue to experience a high level of disability and psychological dysfunction? Health-related quality of life helps to explain how illness affects an individual when clinical indicators alone are insufficient (Blank & Switzer, 2006). When dealing with a chronic illness that has no cure, improving or achieving the highest quality of life possible while living with the illness is the overall goal (S. A. Cudney, Butler, Weinert, & Sullivan, 2002; Verissimo, 2008).

Much of the available research regarding IBD concentrates on the medical aspects of the disease rather than how psychosocial factors relate to IBD. Disease activity associated with IBD is repeatedly reported as painful, troublesome, embarrassing, and unpredictable (Crohn's and Colitis Foundation of America, 2011; Drossman, 1986; Drossman et al., 1991). However, research suggests that for chronic illnesses,

psychological and social factors, as well as physiological factors, contribute to patients' health-related quality of life. For those with IBD, there may be as great or greater impairment in psychological and social domains as in the physical realm, and therefore, greater impact on health-related quality of life (Civan & Pratt, 2007). And, while many physiological factors are beyond a patient's control, an individual's response to illness, namely psychological, emotional, cognitive and social responses, are well within the purview of control and change for an individual. It is from within these responses that the individual can gain some control over the course of his or her illness and quality of life.

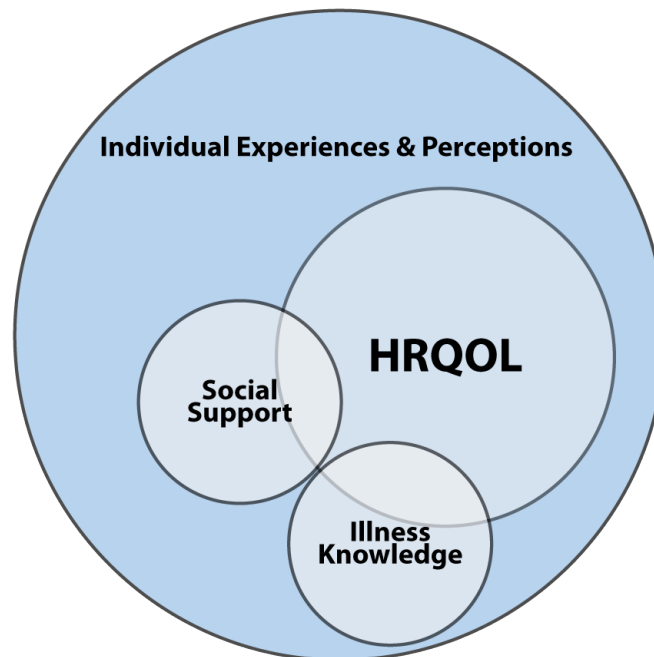


Figure 1. Conceptual model for the study

The conceptual model for this study shown in Figure 1 incorporates Wilson and Cleary's health-related quality of life model, Leventhal's common-sense model, and the two influences on HRQOL of interest in this study, social support, and specifically,

illness knowledge. Wilson and Cleary's health-related quality of life model has emerged as the predominate model used to describe how a variety of individual and environmental factors and perceptions can affect illness outcomes. This model proposes that health-related quality of life is influenced by disease and non-disease factors that either directly or indirectly affect an individual's overall quality of life (Hall et al., 2005). Some physical influences, such as biological dysfunction, and physiological symptoms and their severity, are many times out of a patient's control. Health perceptions, however, or how one views his or her disease and its symptoms, are subjective assessments that are amenable on the part of the patient. So, while health-related quality of life can be influenced by biological and physiological status, Wilson and Cleary's health-related quality of life model illustrates points at which an individual can take action to influence the course of his or her disease, and subsequently, quality of life. Social support and illness knowledge are two such influences over which the individual has control, and subsequently, can affect the social and psychological domains of HRQOL.

Three additional theories relate to this study: Chronic illness theory, social support theory, and social learning theory. These theories will be discussed in greater depth in chapter two.

### Chronic Illness Theory

At the foundation of many chronic illness models, including Wilson and Cleary's health-related quality of life model, is Bandura's social cognitive theory. Bandura's theory is founded in the belief that behavior is guided by the relationship between an individual and the environment, and in an individual's belief in his or her ability to

manipulate the environment in an effort to achieve goals, outcomes and expectations (Graves, 2003). Leventhal's common-sense model takes Bandura's theory further and suggests that individuals generate both cognitive and emotional responses and beliefs to a perceived health threat (Dorrian & Dempster, 2009; Hall et al., 2005; Harvey et al., 2008; McCaul & Goetz, 2008). Subsequently, these individual beliefs, thoughts and perceptions influence coping behaviors, and ultimately, positive or negative adjustment to a chronic illness (Dorrian & Dempster, 2009). Successful adaptation to chronic illness, according to Leventhal's model, is influenced significantly by individual perceptions and appraisal of the chronic illness (Groarke, Curtis, Coughlan, & Gsel, 2004; Krause, 2003).

### Social Support Theory

Social support, which includes informational, emotional, instrumental, and appraisal support, has become an integral component of any successful patient-centered, self-management program. Research on chronic illness shows a consistent positive relationship between social support, health outcomes, and health-related quality of life (S. Cohen, 2004; C. Taylor et al., 2007). Further, social support received from one's peers, specifically peers who share the same chronic illness, is shown to be most beneficial and have the most profound impact (Bunde, Suls, Martin, & Barnett, 2006; Colineau & Paris, 2010; Dennis, 2003; Hall et al., 2005). Provision of social support can help to buffer the negative impacts of chronic illness by assisting with the emotional and physical challenges, and the uncertainty chronic illness presents (Grabinski, 2005; Uchino, Uno, & Holt-Lunstad, 1999; Weiss & Lorenzi, 2008). Additionally, the psychological benefits of social support may directly or indirectly influence physiological processes and physical

health by enhancing recovery, increasing adherence to treatment recommendations, and promoting adaptation to chronic illness (Hill, Weinert, & Cudney, 2006). Current IBD literature reflects this connection as well (Graff et al., 2006; Krause, 2003; Moskovitz et al., 2000; Oliveira et al., 2007; Rogala et al., 2008; Sewitch et al., 2001). Few studies, however, provide information on how IBD patients obtain and perceive social support.

Using Wilson and Cleary's health-related quality of life model, social support can be viewed as an environmental factor over which the individual has a substantial degree of control. The stress-buffering hypothesis, proposed by Cassel and Cobb posits that social support can mediate the potentially harmful effects of stress. First, support may help to lessen the negative appraisal of a stressful event. Second, the availability of support may prevent an individual from resorting to other less successful and potentially detrimental coping behaviors. And, finally, social support may provide a solution or course of action that may decrease the stress thereby minimizing the negative effects while also providing a sense of control over the situation (Uchino et al., 1999).

### Social Learning Theory

There is evidence that gaining specific illness-related knowledge may have a positive effect on health status and quality of life. Studies have shown that patients gain a sense of empowerment and control with increased illness-related knowledge (Barak, Suler, & Bonielnissim, 2008; JH Frost & Massagli, 2008; C. F. van Uden-Kraan et al., 2008). Studies reveal that those with a chronic illness, in particular, want specific information about their disease (Im et al., 2007; Sarasohn-Kahn, 2008; Verma et al., 2001). Perhaps even more importantly, however, those with chronic illness want to know

how their disease will impact their lives. Much of what they want to know is not found in a book or brochure, or even available from their physician. They want to know: Does this ever happen to anyone else? Is what I'm feeling normal? How will the side effects of this treatment affect my job? (Civan & Pratt, 2007; Hall et al., 2005).

Patient learning can be seen as a series of interactions between the patient and potential learning resources within his or her environment. This can include informal learning that results from interpersonal exchanges between patients and the people in their lives. And, it may be that most successful learning occurs within these informal, peer-to-peer interactions (C. Campbell, 2001). Peer learning should be seen as not as an alternative, but as a valuable adjunct to learning in the traditional healthcare setting. Information gained through peer interactions can help to meet the more specific and personal needs that physicians many times cannot. Peers who suffer from the same illness can possess specific knowledge gained from experience that reflects all disease aspects – physiological, psychological, and social (Krause, 2003; Sarasohn-Kahn, 2008). This information is presented in “their own language” and is generally more understandable than the sometimes-complicated medical terminology used by a physician (C. F. van Uden-Kraan et al., 2008). Learning within a community, through interactions with others with similar interests, concerns, or problems, pools contributions from the entire group, and results in a wealth of collective knowledge (Colineau & Paris, 2010; G. J. Johnson & Ambrose, 2006; Marienau & Reed, 2008; Sarasohn-Kahn, 2008; C. Taylor et al., 2007).

Both social learning theory principles and Knowles principles of adult learning can be seen in Leventhal's model (Hale, Kitas, & Treharne, 2007). Social learning theory

views learning as a transactional/transformational process in which we re-evaluate past beliefs and experiences in light of new knowledge and experiences (Marienau & Reed, 2008; E. W. Taylor, 2008). This also reflects a constructivist view of knowledge that contends learning is not merely “acquiring” knowledge but “constructing” knowledge by weaving old and new ideas together (Clark & Rossiter, 2008; Imel & Zengler, 2002; LaCoursiere, 2001; Levine, 2007; E. W. Taylor, 2008). Vygotsky’s social constructivism takes this view a step further and contends that knowledge not simply constructed, but co-constructed. Social constructivists believe learning is a social process wherein groups construct knowledge for one another, and collaboratively create a culture of shared artifacts with shared meanings (UCD, 2010; Vygotsky, 1978). Kolb’s experiential learning theory (1984) and Mezirow’s transformative learning theory (1978) both have a social learning theory foundation as they place great importance on context of learning and the learner’s past experiences (Marienau & Reed, 2008; Merriam, 2005; O’Grady, Witteman, & Wathen, 2008; E. W. Taylor, 2008). People with chronic illness are seen as self-directed learners as evidenced by their motivation and actions to seek out information and resources to address or improve their own health situation (O’Grady et al., 2008). Readiness to learn is a critical issue and can differ greatly with regards to an individual’s past experiences, current knowledge, psychological state, physical condition, and, perhaps most importantly, his or her position within the course of and lifetime with the disease (Heuer, 2007). And, the relevance of illness-specific information is evident as it clearly involves a problem-based, life-centered issue, and thus, can be extremely meaningful to the learner (Heuer, 2007; Largent & Horinek, 2008).



### Research Design

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge. Descriptive research is used to describe characteristics of a population or phenomenon being studied. Descriptive studies also help to demonstrate associations and relationships between individuals and their environment (Gay, 1996). In this study, a self-report survey instrument was initially used to obtain demographic data, and data on how participants report experiences within the online community. Next, qualitative research methods, using semi-structured interviews, were conducted to collect more insightful, narrative data not possible through other research methods. Qualitative methods allow the researcher to expand on descriptive data collected, and find out why participants responded the way they did.

MontanasGotGuts.org (<http://montanastgotguts.org>), an online IBD support community for people in Montana with IBD, served as the platform to provide online social support opportunities for the study sample. Participants were recruited from the membership of the online community. As the population of Montana is relatively small, the incidence of IBD in Montana is small, and the online community membership was low, the researcher was not able to purposefully select participants for the study. Therefore, each of the 40 members was emailed privately and asked to participate in the

study. This email described the nature of the study, its goals, and what participation in the study would entail on the part of the participant (see Appendix C). Those interested in participating in the study were instructed to respond to the email. A second email was sent to each respondent with a link to the online informed consent document and, subsequently, the online survey. Upon completion of the survey, each participant was again contacted via email to arrange a specific time, place, and method for the interview. This process continued until a total of ten participants were recruited for the study.

### Quantitative Phase

Survey questionnaires are sets of carefully designed questions given to a population in order to gain descriptive and statistical information. They also allow various types of data to be collected in an objective and standardized format.

To collect descriptive data, an instrument specific to IBD and the specialized nature of online interventions was created. The purpose of the survey tool was to 1) collect demographic and website usage data, and 2) assess participants experiences and outcomes in the online community. SurveyGizmo (<http://surveygizmo.com>), an online survey tool, was used to collect this data. In addition to the survey, website administration tools and Google Analytics were used to monitor and collect comprehensive member usage data.

To collect descriptive data, the researcher created a 20-item questionnaire specific to IBD and the specialized nature of online interventions (see Appendix D). A table of specifications was developed to establish content validity, and to ensure items contained within the instrument properly reflect the intent of the survey, and the research questions

posed in this study. Further, the instrument was evaluated and reviewed by the researchers advisor and committee members to provide additional content validity. Face validity was established through pilot testing of the instrument. Pilot study participants were interviewed with respect to ease of use, time required to complete the survey, interpretation of questions, and overall impression of the instrument. Minor modifications were made based on these evaluations. The instrument and study protocol were approved by the Montana State University Institutional Review Board (IRB).

After the ten survey questionnaires were completed, data analysis was conducted using Dedoose, an online qualitative and mixed methods research tool. Descriptive statistics in the form of percentages were used to report demographic data, website usage data, members' assessment and evaluation of the website, and members' assessment and evaluation of their experiences with respect to perceived social support, illness knowledge and health-related quality of life.

### Qualitative Phase

The qualitative phase of the study involved a process of inquiry, occurring in a natural setting, and, subsequently, making sense of the information brought forth (Creswell, 2007). This phase was designed to identify themes to assist the researcher, and the Montana healthcare community, in understanding the experiences of those participating in the online community.

All ten participants who agreed to participate in the study and completed the online survey completed the interview portion of the study. Upon completion of the online survey, each participant was immediately contacted via email to set up a time and

place for the interview.

The interview questions were developed, using information obtained through the literature review, to address the research questions posed in the study (see Appendix E). To lend face and content validity, the interview questions were reviewed for accuracy and relevance to the purpose by the researcher's advisor and committee members. Pilot testing of the interview questions was conducted using the same two colleagues who tested the survey instrument.

Semi-structured interviews were conducted to gain additional insight into the psychological processes, perspectives and experiences of these participants (Hall et al., 2005). Semi-structured interviews allow for flexible probing of responses and issues that result from the quantitative phase, and can lead to more insightful and meaningful data. Audio recordings of the interviews were transcribed, coded, and categorized into related theme using Dedoose, a mixed methods research analysis tool. In the deductive phase, data was coded and sorted into categories in line with the goals and research questions put forth in the study. In the inductive phase, additional themes and categories that emerged from the data were recognized. Linkages and relationships between the themes, the existing literature, and the researcher's observations were pulled together and presented in a meaningful conceptual scheme that comprehensively describes the participants' experiences. Participants' activities within the online support community were also observed and recorded by the researcher to lend a deeper layer, and a degree of triangulation to the data (Krause, 2003).

### Definitions

For purposes of this study, the following terms will be used:

1. Autoimmune disease is a condition that occurs when the immune system mistakenly attacks and destroys healthy body tissue. In addition to IBD, multiple sclerosis, diabetes, lupus and rheumatoid arthritis are all known to be autoimmune diseases.
2. Biological and clinical indicators, with regards to IBD, include blood tests (inflammation markers, iron levels), radiological tests (x-rays), pathology reports (tissue biopsies), and physical measurements (body weight and temperature) that together establish the presence or absence of disease activity.
3. Chronic illness (or disease) is an illness that lasts more than three months, or is recurrent. The Chronic Illness Alliance defines a chronic illness as, "...an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life." (Chronic Illness Alliance, 2011)
4. Clinical remission is the state of absence of disease activity and symptoms in patients with a chronic illness or disease. Remission does not mean that the disease is cured, but that the disease is currently quiescent.
5. Crohn's and Colitis Foundation of America (CCFA) is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis. CCFA has over 50,000 members in 40 chapters nationwide.

Montana belongs to the Northwest Chapter based in Seattle (Crohn's and Colitis Foundation of America, 2011).

6. Crohn's disease is an inflammatory disease of the intestines, affecting any part of the gastrointestinal tract from mouth to anus, in which parts of the digestive system become swollen and develop deep sores (ulcers).
7. Health-related quality of life (HRQOL) is "... a broad multidimensional concept that provides information beyond more traditional indicators of health such as mortality and usually includes self-reported measures of physical and mental health." (Centers for Disease Control and Prevention, 2011)
8. Illness-related knowledge, as related to those with chronic illness, means having a working knowledge of their disease and its management.
9. Inflammation is a process by which the body's white blood cells protect us from infection and foreign substances such as bacteria and viruses. In cases of chronic inflammation, as in IBD, inflammation may be associated with redness, swelling, fever, chills, fatigue, loss of appetite and general flu-like symptoms.
10. Inflammatory bowel disease (IBD) is a group of disorders, Crohn's disease and ulcerative colitis, in which the intestines become inflamed (red and swollen), most likely as a result of an immune reaction of the body against its own intestinal tissue.
11. Social network is social structure consisting of friends, colleagues and other personal contacts who share a common interest, and communicate with each other to share information and resources.

12. Social support can be defined as the actual or perceived availability of helpful resources involving the exchange of emotional assistance, information, and tangible resources between two or more individuals.
13. Ulcerative colitis is an inflammatory disease that causes inflammation and sores (ulcers) in the lining of the large intestine, or colon.

#### Limitations of the Study

1. Participation in the online community, and consequently the study sample, consisted of volunteers -- only those who are interested in participating in an online support community, gaining social support and interacting with others. Such individuals may have a predilection for seeking and participating in social support activities.
2. The study assessed participants' experiences in the online community at a point in time early in the existence of the community. Those who join the community at a later time, when the membership might be larger, may benefit from a larger community in which to interact.
3. The study participants needed access to a computer and an Internet connection on a regular basis. Thus, the study sample excluded those without access.

#### Delimitations of the Study

1. This study did not utilize a control group. This study sample included only those in Montana with IBD who participated in the online support community.

Therefore, the results may not be transferrable to those outside of Montana or to healthy counterparts.

2. The researcher in this study was also part of the study population and the website administrator. Great care was taken to avoid researcher bias or influence.

### Assumptions

1. While many may have been hesitant to disclose private, personal, sometimes embarrassing information, it was assumed that participants were honest and open not only in their responses to the survey and interview questions, but also in their interactions within the community.
2. It was assumed that the survey instrument can accurately assess participants' experiences in the online support community, given variances in individual interpretation of the survey questions.
3. Although there is ample research demonstrating the benefits of online support communities and positive contributions to health-related quality of life of those with chronic illness, no such studies exist to demonstrate this same affect on those with IBD.

### Chapter Summary

This chapter presented background on the issue, the problem, purpose and significance of the study, the research questions, an overview of the theoretical



framework, an overview of the research design, definitions pertinent to the study, and limitations, delimitations and assumptions.

Chapter 2 will present a review of the literature regarding chronic illness, IBD, and Internet use in relation to HRQOL. Components of HRQOL, namely social support, illness knowledge and illness representations, were also reviewed.

Chapter 3 will present information concerning the quantitative and qualitative methods that will be used to obtain information from participants in a Montana-specific, online IBD support community regarding their assessments of and experiences within the community, and how their experiences affect their health-related quality of life.

## CHAPTER 2

## LITERATURE REVIEW

The purpose of this study is to examine and evaluate the effects of participation in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) on the health-related quality of life (HRQOL) of the study participants. In addition, the parameters of the participants' perceived social support, illness representations, coping strategies and illness knowledge will be also be assessed as influenced by participation in the online support community, and as potential determinants of HRQOL. And, finally, it is hoped that participation in the online social community can create a network of IBD patients in Montana, and online relationships may transform and evolve into offline, face-to-face relationships.

This literature review will first present information and studies relevant to the status of chronic disease in the U.S. Second, HRQOL and factors that influence and contribute to HRQOL in those with chronic illness will be discussed. Third, the current status of the Internet, and potential benefits for its use by individuals with chronic illness will be presented. Fourth, IBD, and implications of HRQOL and contributory factors will be discussed. Fifth, information regarding IBD and Internet use will be discussed. And, finally, an overview of IBD in Montana, including social support options and Internet use, will be presented.

### Chronic Disease

This section will discuss the psychological and psychosocial issues that affect chronic illness, and present several chronic illness theories that propose how people successfully, or unsuccessfully, adjust and adapt to illness.

The World Health Organization (WHO) (1998) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. When health is lost or compromised, not only is physical well-being affected, but mental and social well-being may also be diminished. For those with acute illnesses such as colds, flu, or even some cancers, physical, mental and social well-being may be temporarily compromised. However, status quo will most likely be restored when the physical attributes of the illness subside. If a disease persists for more than three months, it is considered to be chronic, according to the National Center for Health Statistics (NCHS). Chronic illness is defined as a long-term or permanent disease for which there is no known cure. In most instances, chronic illness can be controlled to various degrees with medication and therapy. Chronic illness can have a dramatic affect on daily life, interfere with social work activities, and, therefore, often require temporary or permanent changes in physical, social and vocational activities (Curtis, 2005).

The Centers for Disease Control (CDC) estimates that almost half of adults in the U.S. are living with at least one chronic illness. Chronic disease is most commonly associated with the elderly, African-Americans, the less educated and those with lower income. The most common chronic illnesses affecting Americans are high blood pressure, lung conditions, heart conditions, diabetes, and cancer (Fox, 2007). So, it comes

as no surprise that the bulk of public attention, and funding, goes to promoting awareness, and providing prevention and treatment options for these conditions (Andrews, 2009; Services, 2006).

### Psychological and Psychosocial Issues

While both acute and chronic illness can affect psychological and psychosocial well-being, chronic illness presents unique challenges, in both scope and degree (Hill et al., 2006; G. J. Johnson & Ambrose, 2006).

The long-term, incurable nature of many chronic diseases requires a mindset that focuses on disease management and adaptation rather than the brief treatment-resolution paradigm associated with acute illnesses. In the absence of a cure, the goal of managing a chronic illness is to maintain the highest quality of life possible while making the necessary physical and emotional adjustments and adaptations (S. A. Cudney et al., 2002). Successful adaptation includes activities that educate, guide, and motivate an individual to take action and control over his or her health to the greatest extent possible (Hill et al., 2006). Understandably, upon initial diagnosis, the onslaught of information and the emotional response may be overwhelming (O'Grady et al., 2008). Feelings of fear and uncertainty are likely to interfere with activities necessary to successfully address and fulfill disease management needs. But, unfortunately, many never fully address these needs even after years of living with a chronic illness.

Many psychological and psychosocial challenges presented with chronic illness are universal; fear, frustration, uncertainty, hopelessness, depression, loneliness and loss of control are commonly seen with chronic illness (S. A. Cudney et al., 2002; Hill et al.,

2006; LaCoursiere, 2001; T. Sullivan, Weinert, & Cudney, 2003). But some chronic illness present additional emotional burdens and stressors, particularly those illnesses that are not well known or widespread, and those that are not outwardly visible to others.

Most with chronic illness will experience a sense of loneliness and isolation at some point during the course of their disease (Casati, Toner, De Rooy, Drossman, & Maunder, 2000; Im et al., 2007; C. van Uden-Kraan, Seydel, Drossaert, Vandelaar, & Taal, 2009; C. F. van Uden-Kraan et al., 2008). The physical limitations that often accompany chronic illness, especially in times of disease exacerbation, can physically isolate an individual (Sewitch et al., 2001). Chronic illness can greatly impact the energy and physical mobility needed to engage in usual social functions and activities.

Isolation may also be self-imposed by an individual resulting in an emotional isolation (S. A. Cudney et al., 2002). Two key components that contribute to emotional isolation are a perceived lack of understanding by others and fear of becoming a burden to others. First, some with chronic illness will not share their concerns, needs and fears with others because they feel that others just cannot relate to their experience (S. Cudney, Sullivan, Winters, Paul, & Oriet, 2005; Hall et al., 2005). In addition, some chronic diseases are associated with a social stigma that many are not comfortable discussing with others (Casati et al., 2000; Curtis, 2005; Hall et al., 2005; LaCoursiere, 2001). Second, some fear or sense that others, even close family, are “tired of hearing about” their disease, or don’t want others to worry, and, therefore, are reluctant to share their concerns or ask for help (Casati et al., 2000; S. A. Cudney et al., 2002; Curtis, 2005; Hall et al., 2005; Lonardi, 2007; C. F. van Uden-Kraan et al., 2008).

When taken to the extreme, self-imposed isolation can take on a level of secrecy. Of course, many chronic illnesses, such as multiple sclerosis or Parkinson's disease, may not offer the option of secrecy. But, many people with chronic illness look and act physically healthy on the surface, and thus, may choose not to disclose their condition to others. Other chronic illness are deemed "socially invisible" due to the fact that they have not achieved social acknowledgement and are relatively unknown to general public (Lonardi, 2007). Those who choose to conceal their disease may feel it is necessary to avoid unwanted attention and consternation from others, and from employers in particular (Lonardi, 2007; Sainsbury & Heatley, 2005). In addition to the resultant isolation, the stress of concealment can invariably worsen a chronic condition. In the larger, social sense, not revealing a chronic illness can only perpetuate its socially invisible nature and further prolong social acceptance (Lonardi, 2007).

### Chronic Illness Theories

A multitude of theories and models exist to help explain adaptation and management of chronic illness. And, while all acknowledge that physiological, psychological, psychosocial and ecological factors, in varying extents, impact adjustment to chronic illness, environmental models focus on multiple environmental factors that influence and direct chronic illness adaption (Curtis, 2005). In contrast to many public health models that are focused on behavior modification and disease prevention, chronic illness models aim to understand emotional and physical adjustment to chronic illness (C. Campbell, 2001; Hall et al., 2005; O'Grady et al., 2008; Sherman et al., 2008; Suwannimitr et al., 2010).

At the foundation of many chronic illness models is Bandura's Social Cognitive Theory. Bandura's theory is founded in the belief that behavior is not only guided by a relationship between an individual and their environment, but also in an individual's beliefs in their ability to manipulate their environment in an effort to achieve goals, outcomes and expectations (Curtis, 2005; Graves, 2003). Leventhal's Common-Sense Model suggests that individuals generate both cognitive and emotional responses and beliefs to a perceived health threat (Dorrian & Dempster, 2009; Hale et al., 2007; Harvey et al., 2008; McCaul & Goetz, 2008). These individual beliefs, thoughts, and perceptions subsequently influence coping behaviors, and, ultimately, adjustment to the chronic illness (Dorrian & Dempster, 2009). The core of Leventhal's model posits that an individual uses "common sense," through their own knowledge and experiences, to form perceptions or "representations" of the illness (Hale et al., 2007). Leventhal's model places the patient at the center of his or her health management by first, recognizing the importance of an individual's emotional response to illness, and, secondly, valuing issues that the individual feels are important (Harvey et al., 2008)

Successful adaptation to chronic illness, according to Leventhal's model, is influenced significantly by individual perceptions and appraisal of the chronic illness (Groarke et al., 2004; Krause, 2003). At the heart of Leventhal's model is the idea of illness representations, or simply, the beliefs and perceptions an individual has about their illness. In an effort to manage these cognitive and emotional representations, an action plan and coping responses are developed by the individual (Dorrian & Dempster, 2009; Hale et al., 2007). The appraisal phase monitors and evaluates the success or failure of

the coping efforts (Dorrian & Dempster, 2009). While coping strategies are the key to active mediation between illness representations and outcomes, illness representations alone can greatly influence illness outcome (Groarke et al., 2004).

### Health-Related Quality of Life and Chronic Disease

This section will define health-related quality of life (HRQOL), discuss how it is impacted by chronic disease, and discuss how individuals' perceived social support, illness knowledge, and illness representations influences their HRQOL.

A few decades ago, clinical and laboratory measurements were generally the sole indicators of illness status and treatment outcomes. In the past two decades, clinicians and researchers have begun to view the patient's own perceptions of his or her health as important factors in research and clinical care. Central to this movement was the question: given the same clinical and biological indicators, why do some patients thrive and gain increased health, while others continue to experience a high level of disability? The concept of quality of life, and in particular, HRQOL helps to explain this discrepancy in patient outcomes. The World Health Organization (WHO) defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (Sainsbury & Heatley, 2005; WHO, 1998). This involves a person's emotional, social and physical well-being and his or her ability to perform tasks of every day living (Donald, 2001; Pulman, 2010; Verma et al., 2001). Although sometimes used interchangeably, the term HRQOL takes the concept of quality of life a step further to



specifically acknowledge the functional effects of illness, and associated treatment plans, as perceived by the patient (Swickert, 2002). Health-related quality of life helps to explain how illness affects an individual when clinical indicators alone are insufficient (Blank & Switzer, 2006). The guiding factor when assessing HRQOL is the patient's perceptions of his or her illness.

The interest and focus on HRQOL prompted the scientific community to develop a model to guide future research and application of HRQOL concepts. Wilson and Cleary's health-related quality of life model has emerged as the predominate model used to describe the how a variety of individual and environmental factors and perceptions can affect illness outcome. Initially, HRQOL indicators were predominately used as a tool to assess treatment outcomes in clinical trials research. But, HRQOL is increasingly becoming a factor in planning overall treatment and illness management in the clinical care setting (Ferrans et al., 2005; Hall et al., 2005).

Wilson and Cleary's model proposes that HRQOL is affected by both disease and non-disease factors (Hall et al., 2005). These factors are categorized into six components that either directly or indirectly affect an individual's overall quality of life. To begin, biological and physiological status can directly or indirectly affect each subsequent factor in the model's progression. Symptom status includes an individual's perceptions of his or her physical, mental, and cognitive condition. Symptom status may directly affect functional status, the ability to perform physical, social, emotional, and cognitive tasks. Health perception is a subjective assessment of all earlier components in the model that results in an individual's overall health evaluation. The final outcome, overall quality of

life, is a subjective assessment of life satisfaction as a whole. In addition to this linear progression of factors, the Wilson and Cleary model also inferred that myriad of individual and environmental factors influence HRQOL. Individual factors include demographic, psychological and cognitive characteristics of the individual.

Environmental factors encompass all external influences such as support provided by family and friends, and geographical, institutional, community and societal influences.

The Wilson and Cleary model clearly illustrates the basic premise of HRQOL; illness severity, as represented by biological and physiological status is not necessarily directly related to quality of life. Rather, this relationship is mediated, positively and negatively, by symptom and functional status and individual health perceptions, as well as individual and environmental influences.

Ferrans (2005) expanded on the Wilson and Cleary model to further explain influences of the various factors. The resultant revised Wilson and Cleary model adds to main components. First, the revised Wilson and Cleary model more clearly defines the scope of individual and environmental factors that can influence HRQOL and acknowledges the changeable and non-changeable nature of these influences. Secondly, while the Wilson and Cleary model represents a linear relationship between all components, the revised Wilson and Cleary model directly proposes a bidirectional relationship between all components. In addition, the revised Wilson and Cleary model allows for direct influence on individual and environmental factors on biological and physiological variables.

### Impacts on Health-Related Quality of Life

When dealing with chronic illness, in lieu of a cure, it stands to reason that improving or achieving the highest quality of life possible while living with the illness is the overall goal (S. A. Cudney et al., 2002; Verissimo, 2008). Traditional health indices alone cannot explain an individual's overall adjustment to and health outcomes regarding chronic illness (LaCoursiere, 2001; Sainsbury & Heatley, 2005; Till, 2003; Verissimo, 2008). A bevy of current research illustrates what might be considered a paradox: in spite of the burden of disease, many people who have a chronic illness achieve or perceive a higher quality of life than their healthy counterparts (Janke, Klump, Gregor, Meisner, & Haeuser, 2005). The most prominent explanation of this phenomenon may be due to the change in perspective and frame of reference for those with chronic illness — from that of a healthy person to others with chronic illness who are worse off (Janke et al., 2005).

The revised Wilson and Cleary model clearly defines individual and environmental factors that can directly or indirectly influence an individual's quality of life. Ferrans, using McLeroy's Ecological Model as a framework, describes these factors in more detail and, most importantly, provides how many of these factors can be controlled and guided by the individual, giving the individual a great amount of control over his or her illness outcome and, ultimately, quality of life.

McLeroy's Ecological Model suggests that an individual is influenced on five levels — two on an individual level and four on an environmental level. Most relevant to the revised Wilson and Cleary model, and amenable to the individual, are intrapersonal influences and interpersonal influences. While some intrapersonal characteristics are not

changeable, such as genetics and demographics, many are open to modification by the individual, and thus, are controllable. But, most notably, an individual's response to illness, namely psychological, emotional, cognitive and social, are well within the purview of control and change for an individual. It is from within these responses that individuals can gain some control over the course of their illness and quality of life.

### Health-Related Quality of Life Influences

Influences on HRQOL of primary interest to this study are an individual's perceived social support, disease knowledge, illness representations, and coping behaviors. While disease knowledge is primarily a cognitive response to illness, perceived social support, personal representations of the illness, and coping behaviors each involve a combined cognitive, psychological and emotional response by the individual.

Social Support. Social support can be defined as the actual or perceived availability of helpful resources involving the exchange of aid and resources from between two or more individuals (C. Campbell, 2001; S. A. Cudney et al., 2002; Krause, 2003; LaCoursiere, 2001; McCormack & Coulson, 2009; Suwannimitr et al., 2010; Uchino et al., 1999). Provision of social support can help to buffer the negative impacts of chronic illness by assisting with the emotional and physical challenges and uncertainty chronic illness presents (Grabinski, 2005; Uchino et al., 1999; Weiss & Lorenzi, 2008). Social support is given and received through an individual's social network. As previously mentioned, use of social support is considered to be a problem-focused, active

coping strategy in that an individual actively attempts to minimize and mediate the affects of chronic illness (Dietrich, 2010). Conversely, social support itself can facilitate more successful coping strategies by facilitating problem-solving, initiating a more positive illness appraisal, and integrating more positive emotional reactions and behaviors (Hill et al., 2006; McCormack & Coulson, 2009).

Social support is generally divided into four categories: emotional, informational, instrumental and appraisal (C. Campbell, 2001; Dietrich, 2010; Olsen & Kraft, 2009; Uchino et al., 1999). Emotional support can increase self-esteem, reduce distress and provide hope through interactions that communicate feelings, concern and empathy, and facilitate listening (C. Campbell, 2001; Civan & Pratt, 2007; Olsen & Kraft, 2009; Till, 2003; Uchino et al., 1999). Informational support involves the exchange of information, advice, suggestions, opinions and experiences, which can help an individual to better understand and cope with his or her illness. Informational support includes not only referrals to third party sources of illness information, but more importantly, encompasses the experiential knowledge that patients gain throughout the course of their illness (Civan & Pratt, 2007). Instrumental support includes practical, tangible, physical assistance that is many times much needed by those with chronic illness such as transportation, financial and other every day needs (Civan & Pratt, 2007; Eichhorn, 2008; Olsen & Kraft, 2009). Appraisal support is a recent offshoot from emotional support and involves affirming acknowledging feelings, emotions, decisions, beliefs, knowledge and decisions, and providing feedback and encouragement (Eichhorn, 2008).

The Stress-Buffering Hypothesis, proposed by Cassel and Cobb, provides the theoretical framework for social support research (Lakey, 2008; Uchino et al., 1999). This theory posits that social support can mediate the potentially harmful effects of stress. First, support may help to lessen the negative appraisal of a stressful event. Second, the availability of support may prevent an individual from resorting to other less successful and potentially detrimental coping behaviors. And, finally, support may provide a solution or course of actions that may decrease the stress thereby minimizing the negative effects while also providing a sense of control over the situation (Uchino et al., 1999).

Actual support transactions, of course, have the real benefits of social participation, and a sense of belonging, in addition to actual support actions received. Perceived support, however, provides an individual with the comfort and knowledge that help will be available if and when he or she needs it. And, although actual social support is beneficial, it is shown that perceived support, or just the knowledge and recognition that social support is or can be available, can be just as, or even more beneficial as actually received support (Krause, 2003; Lakey, 2008; Uchino et al., 1999). Individuals may positively recall past experiences in which they received support, and the associated benefits, and armed with that knowledge, anticipate that they will receive similar help and assistance in the future, if necessary (Lakey, 2008). Actual, received support, although helpful, may also induce feelings of dependence, need, and lack of control, and, therefore, could be seen as less beneficial by some individuals. In addition, research suggests that support that is received informally in the course of everyday life may be more beneficial than that which is sought or requested (Uchino et al., 1999).

*Implications of Social Support.* There is an abundance of research illustrating the influence of social support on physical and psychological health (Colineau & Paris, 2010; P. K. H. Mo & Coulson, 2010; Moskowitz et al., 2000; T. Sullivan et al., 2003). As far back as 1979, a study reported that people with low levels of social contact had mortality rates up to four-and-a-half times greater than those with strong social support networks (Sarasohn-Kahn, 2008). More recent research has supported this finding and, additionally, finds lower levels of mortality in individuals with cardiovascular disease, cancer and infectious diseases such as HIV/AIDS (Olsen & Kraft, 2009; Uchino, 2006). Factors contributing to lower mortality may be explained by potential impacts of social support on specific physiological processes. Of particular interest are reports of social support associated with higher immune function (Olsen & Kraft, 2009), and lower blood pressure (Olsen & Kraft, 2009; Uchino et al., 1999). There is also preliminary data linking social support to inflammatory process that may have major implications in the fields of oncology and autoimmune disease (Uchino et al., 1999). In addition, the psychological benefits of social support may directly or indirectly influence physiological processes and physical health by enhancing recovery, increasing adherence to treatment recommendations, and promoting adaptation to chronic illness (Hill et al., 2006).

*Social Networks.* People are interconnected through their social networks, and it is through these networks that social support is exchanged (Colineau & Paris, 2010). Social networks can consist of family, friends, coworkers and neighbors (Eichhorn, 2008; LaCoursiere, 2001). Social support may be exchanged within these networks through one-to-one interactions or in more didactic, group situations (Olsen & Kraft, 2009).

Social networks can be characterized by structure, interaction and function. Structure reflects the network's composition, size and density, or who the members are and how well they know each other (LaCoursiere, 2001). Interaction comprises the reciprocity, durability, intensity and dispersion of interactions within a network. While interaction involves the ease and frequency with which the function of the network, such as providing information or social support, is disseminated throughout the network (H. S. Campbell, Phaneuf, & Deane, 2004). Most people are socially integrated into a number of networks simultaneously with a wide range of social contacts (Lahey, 2008; C.-P. Lin & Bhattacharjee, 2009; L. Lin, 2006). Those with chronic illness may find it difficult to cultivate and maintain a highly integrated network as the challenges and demands that often accompany chronic illness may leave little time and energy to sustain social relationships (Sewitch et al., 2001). But, recent studies have shown that those with chronic illness may indeed benefit by having fewer, closer relationships rather than a large, less cohesive network (Olsen & Kraft, 2009; Sewitch et al., 2001). Maintaining fewer social connections may result in fewer obligations for reciprocity to be a support provider, which may be an appealing benefit for those with chronic illness (Uchino, 2009).

People most commonly live and interact within their natural social network, which consists of family and friends. But, while natural social networks are the most accessible and readily available, they may not provide sufficient and appropriate social support for those with chronic illness (Colineau & Paris, 2010). Those with chronic illness may feel reluctant to reveal the need for support, even to close family members,



for fear of becoming a burden, or a perceived lack of understanding (S. A. Cudney et al., 2002; Hall et al., 2005; Lonardi, 2007; Skeels, Unruh, Powell, & Pratt, 2010). And, with chronic illness, such support would need to be steady and readily available over a long period of time resulting in prolonged feelings of burden (Uchino, 2009). As a result, people have the propensity to seek out and construct a social network of their own making, one that can provide the social support lacking their natural social network (Colineau & Paris, 2010; Grabinski, 2005; G. J. Johnson & Ambrose, 2006)

*Peer Support.* As mentioned, however important the role family and friends play in providing social support to those with chronic illness, in many instances, they may not be the preferred, or even the most beneficial providers of social support. In one study, only 28.5% of consider engaging social support from family, while only 17% considered friends as a source of social support. Similarly, social support received from health professionals may have even more limited effect than that of family and friends (Colineau & Paris, 2010). Conversely, social support received from ones peers, specifically peers who share the same chronic illness, is shown to be most beneficial and have the most profound impact on those with chronic illness (Bunde et al., 2006; Colineau & Paris, 2010; Hall et al., 2005). Peer support is valued because there is reassurance in talking with others who share similar experiences and circumstances, which can create a mutual understanding (Hall et al., 2005; Krause, 2003; McCormack & Coulson, 2009). In addition, peers, people who are not part of one's natural social network, may be able to offer support without the emotional entanglements often present with family and friends (Colineau & Paris, 2010).

Even within peer relationships, some individuals may be perceived as more helpful than others. When it comes to informational support, Bunde (2006) found that older, more experienced peers were perceived to be “experts” by others and, therefore, seen as more knowledgeable and helpful. For matters of emotional or instrumental support, peers with a similar background, including ethnicity, religious affiliation, demographic and geographical status, were identified as being more helpful.

*Support Groups.* Support groups are social networks purposefully constructed, consisting of peers seeking mutual help and assistance regarding a specific issue or common problem (Krause, 2003). Support groups are different than traditional therapy groups in many ways. First, support groups do not have a preplanned agenda or targeted goal. Second, support groups operate without trained professionals, and many times without any designated leader. This allows for the responsibilities of the groups to be distributed amongst members and can instill a strong sense of group identity, ownership and personal responsibility in its members (Barak et al., 2008; C. Campbell, 2001; Krause, 2003). Third, support groups have an open door policy allowing for members to join or leave at will. In addition, many support groups exist for extended periods of time, years and sometimes decades (Barak et al., 2008). And finally, the goal of a support group is to provide a venue for mutual exchange of social support, whether emotional, informational or instrumental, whereas the goal of professional therapy is usually a change in cognition, emotions or behaviors (Barak et al., 2008; Krause, 2003). Support groups have been around in some form for centuries, but gained popularity in the mid-20<sup>th</sup> century with the development of Alcoholics Anonymous (Barak et al., 2008). At that

time, support groups were seen more as an avenue to provide and obtain emotional relief. In the past few decades, the provision of informational and instrumental support is also seen as benefits of support group participation (Barak et al., 2008; Krause, 2003; McCormack & Coulson, 2009). Emotionally, support groups can promote a sense of belonging and lessen feelings of loneliness and social isolation often experiences with chronic illness (Barak et al., 2008; Broom, 2005; Curtis, 2005; Hall et al., 2005). In addition, because support groups are voluntary and lack the direction and control of a professional or other authority figure, they can foster self-reliance and self-determination in its members (Barak et al., 2008; Broom, 2005). Support groups also allow members to gather information and learn from the experiences of others, which can lead to a better understanding of their condition and assist in decision-making. Instrumental support may also be obtained in the form of physical assistance or exposure to resources beneficial to its members (Barak et al., 2008; Curtis, 2005; Hall et al., 2005).

In traditional support groups, members meet face-to-face at a designated location, usually a hospital or other public community venue. Abundant research exists demonstrating the potential benefits of support groups. Psychologically, social support exchanged in support groups can translate into development of more positive and successful coping skills and behaviors, and result in lower levels of depression, and greater emotional well-being and quality of life (Dietrich, 2010; M. A. Lieberman & Goldstein, 2005; T. Sullivan et al., 2003; Till, 2003; C. F. van Uden-Kraan et al., 2008). Face-to-face support groups also allow for socialization and a chance to physically engage with one's community. Participation may also provide exposure to related

community and civic activities, and therefore, provide increased social integration that many with chronic illness lack (Im et al., 2007). Support group may also promote more positive health outcomes. One study of breast cancer patient randomly placed in a support group found that those participating in the support group lived twice as long as those who received routine medical therapy only (Uchino et al., 1999).

Although there is ample research demonstrating the benefits of support groups for those with chronic illness, participation rate are generally low (Sherman et al., 2008). A number of reasons have been proposed to explain this paradoxical lack of participation. While some may enjoy and even relish the social atmosphere of traditional support groups, many people are uncomfortable sharing personal medical information, feelings and emotions face-to-face with others, many of whom are strangers. Similarly, many with chronic illness are reluctant to divulge information or exhibit emotions to people they know from their extended community social network (Im et al., 2007). Many people have misconceptions as to the support groups and may question the purpose of the group, or even mistrust the intent. Others simply feel that the support group would not be beneficial to them and not provide relevant, up-to-date information. Lack of access and/or transportation can be a major obstacle to participation, especially for those with chronic illness and those in rural areas (Im et al., 2007; Sherman et al., 2008). Lack of awareness also plays a role in low support group participation as many may not know where and when meetings are, or even that the support groups exists. And finally, the lack of support group referral from a patient's physician, or other healthcare professionals, not only contributes to the lack of awareness, but also negatively affects a patient's

motivation and likelihood to participate (Sherman et al., 2008). Research bears out this lack of participation. A study at one large HMO revealed that only 3 to 12% of cancer patients participated in traditional support services, including support groups, provided in the community (Eakin & Strycker, 2001; Sherman et al., 2008). Similarly, a study of lung cancer patients at the Mayo Clinic revealed that only 21% had a modest interest in attending a hospital-based support group; subsequently, the actual participation was a dismal 10 to 30% (Quin et al., 2010). Further examination of the literature reports similar participation rates between 5 to 31% (Bauman, Gerverey, & Siegel, 1992; Eakin & Strycker, 2001; Guidry et al., 1997; Pascoe, Edelman, & Kidman, 2000; Plass & Koch, 2001; Sherman et al., 2008).

Despite the low participation rates purported in the literature, support group participation does appeal to some people with chronic illness. Characteristics of both the participant and the group itself may help to explain why some support groups are successful, and why some people find them beneficial. The typical support group participant is young, white, middle-class, well educated and female. Participants tend to be further removed from diagnosis, and more likely to perceive their illness as severe and stressful. In addition, those who anticipate benefits, and are encouraged to participate from family and friends are more likely to participate. Similarly, patients are more likely to participate in a support group when their physician recommends they do. And finally, disease-specific support groups garner higher participation rates than do groups comprised of myriad of chronic illnesses. Interestingly, studies reveal that breast cancer patients exhibit the highest support group participation rates compared to other chronic

illness. This may be explained, in part, by the high level of media attention and public awareness breast cancer imbues, and, subsequently, higher availability and access to breast cancer support groups (Eakin & Strycker, 2001; Krizek, Roberts, Ragan, Ferrara, & Lord, 1999; Sherman et al., 2008). It is not surprising, therefore, that woman with breast cancer most closely fit the typical demographic explained earlier.

Studies show that support group participation for those with chronic illness can be beneficial, but participation rates in traditional support groups continue to be low. Efforts to increase participation may address several factors; increase awareness and access to groups, increase advocacy and referral by physicians, target underserved demographics. Provision of additional or alternate delivery methods may also help to alleviate barriers and allow for increased participation by a more broad and diverse population.

Illness Knowledge. Patient education is a staple of medical care in the traditional healthcare system, and is especially important for those with chronic illness. Patient education generally includes information about the diagnosis, causes, treatment, and potential outcomes and impact of an illness (Dorrian & Dempster, 2009). It can be defined as experiences designed to improve a patient's knowledge and behavior in order to improve his or her overall health status (Blank & Switzer, 2006). Unfortunately, patient education is frequently seen as only a one-way flow of information, usually from a physician or other healthcare professional to the patient. But, the simple dissemination of information itself does not guarantee that a patient will "learn" what he or she needs to know or wants to know, or what the physician feels is critical for the patient to know. Learning is a process that involves bringing together the information received with our

own cognitive, emotional and environmental influences and experiences, and our attempts to make sense of and apply what is learned.

Studies reveal that, more than anything, those with chronic illness want specific information about their illness (Im et al., 2007; Sarasohn-Kahn, 2008; Verma et al., 2001). Information regarding symptoms, diagnosis, test results, treatment options, medications and side effects are commonly the focus of most patient education programs (Civan & Pratt, 2007; O'Grady et al., 2008; Seeman, 2008; C. F. van Uden-Kraan et al., 2008). But, from the point of view of those with chronic illness, information needs fall into two categories: emergent events and future events (Civan & Pratt, 2007). Emergent events require immediate information to address current problems or issues — Is this symptom serious? What should I do now? Those with chronic illness also look toward future events, and want the information necessary to prepare for possible outcomes and challenges — What will happen? What if this happens? Perhaps even more importantly, however, those with chronic illness want to know how their chronic illness will impact their lives — How will I feel? Is what I'm feeling normal? Much of what people with chronic illness want to know is not found in a book, brochure, or even from their physician — How will the side effects of this treatment affect my job? Has this ever happened to anyone else (Civan & Pratt, 2007; Hall et al., 2005)?

Information seeking is a multifaceted process of acquiring and evaluating information that involves interactions between an individual and his or her environment (H. S. Campbell et al., 2004; O'Grady et al., 2008). Information seeking in itself is seen as a positive, active coping strategy, whether or not sound, usable information is gained.

Information seeking is opportunistic and situational as most people only seek out information when problems or issues occur (O'Grady et al., 2008). But, before people can use the information it must be available and accessible, and provided in a useful and understandable format (H. S. Campbell et al., 2004).

*Information Sources.* Traditionally, patient education was something relegated to the doctor's office, health clinic, or other formal setting. Learning in formal settings such as this is usually purposeful and intentional as learning, or perhaps merely acquiring knowledge, is the primary goal. The vast majority of what we learn as adults occurs informally, in settings outside of a classroom or other educational setting. Informal learning can also be purposeful as the patient actively seeks out the information he wants or needs. Further, informal learning can be incidental, occurring during every day activities without intention on the part of the learner (Mundel & Schugurensky, 2008). And, it is shown that patients will more likely follow a continuum, using informal learning channels before resorting to formal learning environments (O'Grady et al., 2008).

Patient learning can be seen as a series of interactions between the patient and potential learning resources within his or her environment including. At its most informal, patients are exposed to, even bombarded with, health information everyday through popular media and culture. It is difficult to watch television for more than five minutes without seeing a pharmaceutical advertisement, or a public service announcement soliciting funds or awareness for a disease. Movies and television shows regularly feature characters fighting to overcome a condition (Cima & Anderson, 2007;



Heuer, 2007; Stuckey & Kring, 2007). And, of course, with the pervasiveness of the Internet, we have never before had such access and exposure to medical information (Bunde et al., 2006; Cima & Anderson, 2007; Esquivel, Meric-Bernstam, & Bernstam, 2006; Fox, 2010; Im et al., 2007; Sarasohn-Kahn, 2008). The old adage “buyer beware” has never been more true as patients must be constantly aware of misinformation and misleading information, and underlying agendas and bias when evaluating such information (Tisdell, 2007).

Informal learning can also result from interpersonal exchanges between the patient and the people in his or her life. It is within these dyadic relationships where most successful learning can occur (H. S. Campbell et al., 2004). And, while family and friends are the closest, most consistent relationship that a patient may have, they are not usually seen as a valuable source for disease information (Colineau & Paris, 2010).

The physician remains the primary source of information for those with chronic illness (Cima & Anderson, 2007; Colineau & Paris, 2010). A recent National Cancer Institute study revealed that not only are physicians the preferred source for health information, this preference increased from 2002 to 2008 (Fox, 2010). Patients are staying connected to their physicians not only to discuss complex, sensitive issues, but also to verify what is learned elsewhere (Colineau & Paris, 2010). But, there are many barriers to receiving timely and adequate information from the physician. First, in today’s healthcare system, time constraints and insurance restrictions can decrease opportunities for patient-physician interaction (Cima & Anderson, 2007). Second, for those newly diagnosed with a serious chronic illness, any information given initially from the

physician may not be received or comprehended as the stress and trauma of the event may negatively affect memory and learning (K. Taylor, 2006). In addition, much of this new information is complicated and overwhelming, and often requires more than a quick office visit (O'Grady et al., 2008). Commonly, the physician or other health professional will provide literature to supplement the office visit, but studies show that printed literature is neither valued nor successful as a patient-learning tool (Harris, Smith, & Veale, 2005). Lastly, and perhaps most importantly, there are some questions, such as the psychological, psychosocial and emotional aspects of the disease, for which a physician does not have an answer (Casati et al., 2000).

Peer exchange should be seen as not as an alternative, but as a valuable adjunct to learning in the traditional healthcare setting. Information gained through peer interactions can help to fill the more specific and personal needs the physician fails to meet. First, peers, who suffer from the same illness, possess specific knowledge gained from experience reflecting all disease aspects — medical, psychological, and social (Krause, 2003; Sarasohn-Kahn, 2008). Second, this information is presented in “their own language” that is generally more understandable than the sometimes complicated medical terminology used by a physician (C. van Uden-Kraan et al., 2009; C. F. van Uden-Kraan et al., 2008). And, finally, peer relationships do not contain the power/authority dynamic seen within the patient-physician dyad. As a result, patients may feel more comfortable and open to asking for specific information from peers than they would from their physician.

*Peer Information Exchange.* People genuinely like to help each other, and sharing their knowledge and experiences with other (Imel & Zengler, 2002). Peer information exchange is a collaborative, problem-solving process in which the patient presents a problem, which, in turn, solicits responses from one or more people (Francesc Casellas, Lopez-Vivancos, Casado, & Malagelada, 2002). Information offered by peers can be placed into four categories (Civan & Pratt, 2007). Action strategies are specific advice or actions to take regarding a problem. Recommended knowledge can be factual explanations, personal experiences or opinions shared about a problem. Suggested approaches present new ways of thinking and attitudes towards the illness or problem at hand. Information resources direct the patient towards external sources of information such as a website or medical literature, another more knowledgeable peer, or a medical professional. Each of these interactions reflects the valuable knowledge and experience peers can offer to each other (Freiler, 2008; C. F. van Uden-Kraan et al., 2008).

*Adult Learning Theories.* At the foundation of successful patient learning, however, are the basic tenets of adult learning — adults choose what, where, and how they will learn, and are the evaluators of their own learning (Heuer, 2007; Merriam, 2008). Knowles Principles of Adult Learning are reflected appropriately and accurately in those with chronic illness (Knowles, Holton, & Swanson, 1998). People with chronic illness are seen as self-directed learners as evidenced by their motivation and actions to seek out information and resources to address or improve their own health situation (O'Grady et al., 2008). In addition, their readiness to learn is a critical issue and can differ greatly with regards to an individual's past experiences, current knowledge,

psychological state, and, perhaps most importantly, their position within the course and lifetime with the disease (Heuer, 2007). And, finally, the relevance of chronic illness information is evident as it clearly involves problem-base, life-centered issue, and thus, can be extremely meaningful to the learner (Heuer, 2007; Largent & Horinek, 2008).

Adult learning theories place great importance on both the context of learning, and the past experiences of the learner. The physical, sociocultural and emotional context can affect not only the learner's readiness, but also influence the learner's motivation and ability to seeking knowledge (Heuer, 2007; Merriam, 2008). In addition, adult learners place great importance and value in incorporating prior experiences and knowledge into their learning process (Heuer, 2007; Hugo, 2002; Largent & Horinek, 2008; Richter-Hauk & Arias, 2008). Lindeman, in describing its importance, stated that adult learners "dig down into the reservoirs of their experience before resorting to texts and secondary facts" (Knowles et al., 1998, p. 37).

Regardless of the source of disease information, several learning and adult learning theories can help to frame the learning that takes place within the chronic illness experience. Social Learning Theory contends that learning occurs within the social context of our lives (Knowles et al., 1998; Pulman, 2010). Further, an individual's thoughts, emotions, and behaviors, and the environment exhibit reciprocal influences on learning. Each influence, however, can be shaped or modified by the individual, potentially giving the learner a great deal of control (C. Campbell, 2001).

Similarly, other learning theories have a similar conceptual view of the learning process and are highly applicable to patient learning. Although subtle differences are

seen, at the core of these theories is a similar, multi-stage process through which an individual “learns.” Kolb’s Experiential Learning Theory, Zull’s Four Pillars of Learning, and Mezirow’s Transformative Learning Theory all have Social Learning Theory foundation as they place great importance on context of learning and the learner’s past experiences (Knowles et al., 1998; Marienau & Reed, 2008; Merriam, 2008; O’Grady et al., 2008; E. W. Taylor, 2008). They also see learning as a transactional/transformational process in which we re-evaluate past beliefs and experiences in light of new knowledge and experiences (Marienau & Reed, 2008; E. W. Taylor, 2008). This also reflects a constructivist view of knowledge that contends learning is not merely “acquiring” knowledge but “constructing” knowledge by weaving old and new ideas together (Clark & Rossiter, 2008; Conceicao, 2007; Grabinski, 2005; Imel & Zengler, 2002; LaCoursiere, 2001; Levine, 2007; O’Grady et al., 2008; Rocco, 2007; E. W. Taylor, 2008). Vygotsky’s social constructivism takes this view a step further and contends that knowledge not simply constructed, but co-constructed. Social constructivists believe learning is a social process wherein groups construct knowledge for one another, and collaboratively create a culture of shared artifacts with shared meanings (UCD, 2010; Vygotsky, 1978). The framework presented in these theories can also be seen in Leventhal’s model (Hale et al., 2007).

*Transformative Learning Theory.* Mezirow’s Transformative Learning Theory is learning achieved through interaction and dialog with others, which makes meaning of our lives (Mezirow, 2000). With Mezirow’s theory, true and complete learning requires a fundamental shift in perspective – towards us, our world, and our place in it (Eisen, 2005;

Fiddler & Marienau, 2008; Freiler, 2008; Grabinski, 2005; Merriam, 2005; Mezirow, 2000; E. W. Taylor, 2008). And, while educational theorists argue as to the extent and depth of this perspective shift, Mezirow insists we need to change our entire perspective of life for transformative learning to take place (Merriam, 2005).

There are many variations, modifications and evolutions of Mezirow's theory. But central to any variation of Transformative Learning Theory is a four-stage process.

First, transformative learning is triggered by problem, dilemma or disorienting event (Butler, 2005; E. W. Taylor, 2008). These events can be anticipated transitions that occur in life such a marriage or retirement, or they can be unanticipated, often traumatic, painful and challenging, life crises such as illness (Merriam, 2005). In any case, these events cause us in some way to question and re-examine our old thought, beliefs and behaviors in an attempt to make meaning of our new reality (Merriam, 2005; Wolf, 2005). Transformative Learning Theory is often an uncomfortable, sometimes painful process as it is often easier to hold onto old habits, beliefs and thoughts (Wolf, 2005). It is not until the discord within our old knowledge and beliefs and our reality reaches a point where resolution is needed.

Reflection is, perhaps, the most critical component of Transformative Learning Theory and has many facets. In general, reflection is the process of examining our own thought, feelings and beliefs, confronting new and different ideas received through discourse with others, and, in the end, deciding to accept or reject and new-found beliefs or knowledge (Fiddler & Marienau, 2008; Marienau & Reed, 2008; E. W. Taylor, 2008; Zull, 2004). For those with chronic illness, past experiences with illness, and perhaps

about this disease specifically, influence our current perceptions (Diefenbach, 2008; Eisen, 2005; Hale et al., 2007). During reflection we may become aware that our view of the problem or condition is limited or distorted, and are open to alternative views, opinions and ideas (E. W. Taylor, 2008). These views may include family, friends, peers, experts, and popular culture, but the experiences of others who have the same condition are especially influential and receive greater consideration (Freiler, 2008; Grabinski, 2005; E. W. Taylor, 2008). We consider the relevance, usefulness, and validity of these new ideas, while reassessing our own beliefs and assumptions (Clark & Rossiter, 2008; Fiddler & Marienau, 2008; Stein, 2002; E. W. Taylor, 2008). The reflection process is complete when we choose to either accept or reject this new knowledge or perspective (Marienau & Reed, 2008; E. W. Taylor, 2008; Zull, 2004).

The third step in Transformative Learning Theory is action. The goal is a change of perspective and a new way of seeing ourselves in the world, but we must test our new perspectives, beliefs and behaviors to see if they do indeed work within our reality (Marienau & Reed, 2008; E. W. Taylor, 2008; Zull, 2004). The reflection and action steps may be revisited many times before this new belief system settles in. In the final step, reintegration, the new perspective is incorporated into our entire life and way of being. For those with chronic illness, it means a new perspective of the individual, the disease, and the meaning of the disease in our life (Merriam, 2005).

*Implications of Illness Knowledge.* Although research is scarce, there is evidence that illness knowledge can have a positive effect on health status and quality of life. First, studies have shown that patients gain a sense of empowerment with increased illness

knowledge (Barak et al., 2008; Drossman, 1995; J. Frost & Massagli, 2009; C. F. van Uden-Kraan et al., 2008). Similarly, some studies reveal decreased anxiety and stress, more confidence and greater feelings of control (Casati et al., 2000; Dorrian & Dempster, 2009; Drossman, 1995; J. Frost & Massagli, 2009; Krause, 2003; Sainsbury & Heatley, 2005). Further, better-informed patients report to be more satisfied and compliant with treatment (Cima & Anderson, 2007). Even if relevant and useful knowledge is not gained, many report that just the process of seeking information, and “feeling more educated” can be empowering in itself (Fox, 2010). And, this sense of empowerment increases when the source of information is not an authority figure or health professional (Casati et al., 2000; Dorrian & Dempster, 2009; Drossman, 1995; J. Frost & Massagli, 2009; Krause, 2003; Sainsbury & Heatley, 2005). Patients also report feeling more confident, and “get more out of” visits to the physician (Colineau & Paris, 2010; Drossman, 1995; Krause, 2003). In addition, providing information for others has shown to be empowering (Barak et al., 2008). And, finally, illness information may be most beneficial to those with chronic illness at the time or soon after diagnosis (C. van Uden-Kraan et al., 2009).

There is some concern that increased illness knowledge can have negative affects on patient well-being and quality of life. Most notably, some see knowledge increasing anxiety and concerns about potential complications and disease outcomes (Casati et al., 2000; Verma et al., 2001). In addition, conflicting knowledge from multiple sources can also be troubling, and may result in decreased quality of life (Fox, 2010).



*Learning Communities.* People have an inherent need to form communities (Hugo, 2002; G. J. Johnson & Ambrose, 2006; Lawrence, 2002). In learning communities, through interaction with other with similar interests, concerns, or problems, people collectively build knowledge by pooling contributions from the entire group (Colineau & Paris, 2010; G. J. Johnson & Ambrose, 2006; Marienau & Reed, 2008; Sarasohn-Kahn, 2008; C. Taylor et al., 2007).

Foremost, members of a learning community share a common interest or purpose — but common purpose alone is not enough to form a successful community (Drennon, 2002; Grabinski, 2005; Imel & Zengler, 2002; Lawrence, 2002; Stein, 2002). Learning for oneself and the community, and it is imperative that knowledge is generated and shared by all members, and that each member's contributions are valued and respected (Clark & Rossiter, 2008; Drennon, 2002; Marienau & Reed, 2008; R. O. Smith & Dirks, 2007; Stein, 2002). In addition, it is an informal atmosphere in which members educate each other without reliance on outside “experts,” and the entire group shares leadership responsibilities community (Hugo, 2002; Imel & Zengler, 2002; Lawrence, 2002; C. Taylor et al., 2007). Successful learning communities foster a safe, supportive and intimate atmosphere, separate from the demands of everyday life, in which strong emotional bonds can form (Bersch & Lund, 2002; Colineau & Paris, 2010; Im et al., 2007; Merriam, 2008). And, finally, as the adage goes, groups are often “smarter than the smartest people in them” (Surowiecki, 2005). Learning groups capitalize on the collective wisdom of groups, and actively vet information to ensure local knowledge is timely and accurate (Colineau & Paris, 2010; O'Grady et al., 2008; Stein, 2002).

While learning communities can provide valuable learning opportunities for those with chronic illness, they are not without their challenges. Though leadership responsibilities are shared amongst group members, the underlying philosophy, values, protocols and responsibilities of the group must be clearly delineated (Hugo, 2002; C.-P. Lin & Bhattacharjee, 2009). Furthermore, there must be a commitment from a core group of members to ensure the groups sustainability, and to provide socialization and guidance to new members (Hugo, 2002). And, finally, as with any diverse group, consideration and respect must be given to individual variations in communication and learning styles (English, 2006; Levine, 2007).

*The Expert Patient.* The concept of the “expert patient” has developed in recent years due in great part to the abundance and accessibility of health information. Some patients may feel they know more than their physician — and that may be true, for some people. But, does this make them an “expert?” An expert, by definition, is one who controls the production of knowledge, decides what is valid and legitimate, and decides who gets the information and how it is disseminated. Indeed, knowledge is power. But, in the patient-physician paradigm, neither have all of the answers. While physicians, traditionally considered the expert carry expertise regarding disease diagnosis, etiology, prognosis and treatment options, the patient contributes expertise by conveying the experiences, attitudes values, preferences and feelings that only a patient can possess degree (Hardy, 2004). Therefore, illness knowledge is a shared expertise between the patient and the physician. Further, by this designation, every patient is an expert in his or her own disease.

Illness Representations. Illness Representations are a patient's beliefs and expectations about his or her illness (Diefenbach, 2008; Groarke et al., 2004; Krause, 2003). Illness representations comprise part of Leventhal's model and are a critical in determining adjustment to chronic illness that objective disease variables cannot fully explain (Groarke et al., 2004). Illness representations are cumulative — new symptoms and disease knowledge are integrated with an individual's past experiences and knowledge in an effort to make sense of the new illness-related paradigm (Hale et al., 2007). Illness representations allow an individual to give personal meaning to their illness.

Illness representations are comprised of six attributes involving both cognitive and emotional responses to illness (Diefenbach, 2008; Dorrian & Dempster, 2009). Together, as illustrated in Leventhal's model, illness representations act as a mediator towards choosing successful adaptive coping behaviors.

The first step in creating an illness representation is to identify or name the illness. This is done through a combination of disease knowledge and proper assessment of symptoms. Timeline refers to an individual's beliefs about the duration and course of the illness. Consequences are perceptions and the believed impacts of the illness. Cause involves perceptions as to possible causes of the illness, whether hereditary, internal or external. Control/cure involves perceptions regarding an individual's to control the illness through successful coping behaviors. Coherence refers to the individual's ability to put all of this information together to form a coherent and rational view of his or her illness.

Research regarding illness representations has been on the rise in recent years. And, although illness representations are still a relatively novel subject, some important trends are coming to light. Dorrian (2009) demonstrated how illness representations play a significant role in adjustment to chronic illness. Specifically those who perceive their illness as more serious, chronic and cyclical exhibit poorer illness adjustment. Conversely, those with a perception of more personal control, and a more coherent understanding of their disease experienced more positive illness adjustment. Similarly, Groarke (2004) found that individuals who viewed their illness as more serious, less controllable, long lasting with serious consequences experienced higher levels of pain and depression, and poorer physical and psychological adjustment to the illness.

One example of successful illness adjustment is normalization. Through illness normalization the individual develops a narrower, more restrictive illness representations with defined and precise limits (Krause, 2003). For example, one might perceive greater level disease understanding, knowledge and control thus eliminating much of the misinformation and unnecessary negation thoughts and connotations held. This, in turn, can free an individual from unnecessary, and often self-imposed restrictions, and, perhaps, make the illness less pervasive to daily life (Krause, 2003). Ultimately, a positive illness representations and subsequent illness adjustment may shift the mindset from that of a “sick” person to someone who is merely “different” and needs special care (Drossman, 1986; Krause, 2003). With greater acceptance of oneself with the illness, and recognition of, but not submission to, one’s limitations, individuals can learn to live a “normal” life in spite of the illness.

*Coping Strategies.* As illustrated in Leventhal's model, individuals with chronic illness engage in a variety of coping activities in an attempt to mitigate the affects of chronic illness (Dorrian & Dempster, 2009; Groarke et al., 2004). Coping can be defined as the cognitive and behavioral efforts one takes to minimize and/or alleviate stress that otherwise may be disruptive and problematic to one's life (Lazarus & Folkman, 1984; Moskowitz et al., 2000; Pearlin & Schooler, 1978). Coping involves having adequate and available resources including education and knowledge, social support, and a psychological make-up that allows for development of self-esteem, self-efficacy and control. Coping strategies, on the other hand, are the actual activities and behaviors an individual takes to address the stressful event, in this case, chronic illness.

Much research surrounding chronic illness and coping is framed within the Transaction Stress and Coping Theory put forth by Lazarus and Folkman (1984). This theory postulates that coping cognitions and the subsequent behaviors are a result of, first, an individuals appraisal of the stress, second, the controllability of the stress, and third, evaluation of his or her coping efforts (Lakey, 2008; Lazarus & Folkman, 1984).

Coping strategies generally fall into two categories: problem-focused and emotion-focused. Problem-focused coping involves efforts to directly confront the stress in an effort to alter or ameliorate the situation. Problem-focused coping strategies include pro-active, problem-solving activities such as planning, and seeking information and social support (Groarke et al., 2004; O'Grady et al., 2008). On the other hand, emotion-focused coping are aimed at managing emotional responses to stress in an effort to

minimize the problem. Emotion-focused are generally passive and include avoidance, denial, and cognitive reappraisal.

Problem-focused coping is more likely associated with successful illness adaptation and improved outcome (Uchino, 2009). Social support is one such active coping strategy that has shown to increase positive adaptation to chronic illness (Hill et al., 2006; McCormack & Coulson, 2009; P. K. H. Mo & Coulson, 2010; Rogala et al., 2008; C. F. van Uden-Kraan et al., 2008). Although generally associated with negative outcomes, emotion-focused coping has shown to have both positive and negative outcomes (Dorrian & Dempster, 2009; Groarke et al., 2004; P. K. H. Mo & Coulson, 2010). Acceptance, positive reinterpretation, distraction, and reliance on religion and prayer have shown to be successful coping strategies (Groarke et al., 2004; P. K. H. Mo & Coulson, 2010). Conversely, maladaptive emotion-focused coping behaviors such as self-blame, avoidance, pessimism and escape are negatively associated with quality of life (Moskovitz et al., 2000; Sainsbury & Heatley, 2005).

One emotion-focused coping strategy that involves the cognitive reappraisal of illness is social comparison. Social comparison is the process whereby individuals compare their condition and status to others in an effort to assess and define his or her own normality (Hall et al., 2005; Sherman et al., 2008). In particular, downward comparison has shown to have a positive affect on illness adaptation (Hall et al., 2005; C. F. van Uden-Kraan et al., 2008). When another person's situation is perceived to be significantly worse, an individual's own illness may be perceived as less of a threat, and therefore, he or she may appraise his or her own condition as less bleak. The use of

upward social comparison has mixed reviews. Some studies suggest that upward social comparison can be a source of inspiration and advice, but it is less often cited as a beneficial activity (C. F. van Uden-Kraan et al., 2008).

### The Internet and Chronic Disease

This section will discuss the Internet and its influence on health and chronic disease, how those with chronic illness use the Internet to find pertinent information, and how social media, specifically online health communities, have impacted access to information and support.

There is no denying the pervasiveness of the Internet today. In 2006, Time declared that “YOU,” as in we, the people, were their “person of the year” due to the way we control the creation and flow of media with Internet use (Grossman, 2006). In June, 2010, North America, 77.4% use the Internet, up 146.3% from 2000. And, in the U.S. alone, 77.3% of Americans use the Internet ("United States Internet and Facebook User Statistics," 2010). Even with those high numbers, however, there are still barriers to Internet access, and in particular, access to broadband access that can allow users to experience richer, social Internet activities (Fox, 2010). Internet usage for seniors is notably less than the general population – 1.5% in 2004 – due in part to lack of technological experience, financial restrictions and visual impairments (Fox, 2010; Quin et al., 2010; "United States Internet and Facebook User Statistics," 2010). Other demographic groups show similarly low Internet usages rates, namely those of lower income, less education, and those in rural areas (Fox, 2010). One recent study cited home

Internet access amongst rural Americans at 50% (Quin et al., 2010). In recent years, mobile Internet access has become the fastest growing segment of Internet use. Not only has Wi-Fi access at home and in public spaces increased exponentially, but eight in ten adults, two-thirds of seniors alone, have cell phones (R. A. Cohen & Stussman, 2010).

### Social Media

The core element of the Internet has always been its capacity to facilitate communication (O'Grady, 2008b). But, the degree and depth to which communication is possible has evolved rapidly over the past decade. During the Web 1.0 era, the infancy period of the Internet, the Internet was mainly an information-gathering machine. Websites consisted of static pages, users simply “searched and read” information (Sarasohn-Kahn, 2008). Content was controlled and authored by “one” source for “many” to read (O'Grady, 2008b; Patterson, 2010; Sarasohn-Kahn, 2008). Websites were not designed with interactivity in mind, and, what limited interactivity there was consisted of the occasional comment, email and listservs read (O'Grady, 2008b; Patterson, 2010).

The advent of Web 2.0 has seen the growth of social media technologies through the Internet. Social media is the enhanced generation of web-based communication tools and practices people use to facilitate open collaboration, sharing, and creativity between people (Pulman, 2010; Sarasohn-Kahn, 2008). Social media has transformed the Internet into a participative venue that allows individuals, even those with little or no technological skills, to create content, share information, opinions and connect directly with others (Chou, Hunt, Beckjord, Moser, & Hesse, 2009; Pulman, 2010; Sarasohn-



Kahn, 2008). More than any other time in history, people are able to look to peers, and strangers, for advice and information at any time of the day no matter where they are located in the world (Chou et al., 2009; Fox, 2009). Applications such as blogs, chat rooms, forums, instant messaging, video conferencing, YouTube, and Twitter and allowed Internet users unprecedented control over their information and communication needs (Sarasohn-Kahn, 2008).

### Social Networks

The evolution of social media had dramatic affects on the Internet. Social network site began appearing in 2004 with the advent of Facebook. By 2008, Facebook had 100 million users — today there are over 600 million active users and counting (Facebook, 2010). In August 2010, 43% of all Americans had a Facebook account (Fox, 2010). In general, social network use has quadrupled from 2005 to 2009. And, although Facebook and MySpace are the most well-known social network site, especially with younger people, in 2009, 47% of all Internet users belonged to some type of social network, up 12% from the previous year (Fox, 2010). And, while seniors are generally on the lower end of Internet use, use of social networks by seniors continues to grow, doubling from 7% of senior Internet user in 2008 to 15% in 2010 account (Fox, 2010).

Social networks sites are online platforms that focus on building and reflecting social networks and relationships among its users (Colineau & Paris, 2010; G. J. Johnson & Ambrose, 2006; Sarasohn-Kahn, 2008). Social network sites allow users to create a profile, and then choose “friends” who can or cannot see it, and who can communicate with you. Another feature of social network sites allows users form subgroups, or virtual

communities, of members with common interests or activities all within the confines of the website. The most identifiable feature of social network sites is the ability to post a status update, a short message, to relay any thoughts, feelings or ideas you may have to your friends (Boyd & Ellison, 2007; Olsen & Kraft, 2009; Subrahmanyam, Espinoza, Waechter, & Reich, 2008). Social networks sites are integrated with many social media tools and applications to help facilitate communication and sharing among its members (Colineau & Paris, 2010; G. J. Johnson & Ambrose, 2006; Sarasohn-Kahn, 2008).

Social network sites have several characteristics that distinguish them from other online communities and websites. First, they more often support pre-existing social relationships rather than promoting new ones (Lampe, Ellison, & Steinfield, 2006; Olsen & Kraft, 2009; Subrahmanyam et al., 2008). People who befriend each other in these sites usually have an offline connection that is bridged, and sometimes strengthened, through site (Subrahmanyam et al., 2008). Social network sites are a popular platform for people to keep in contact with distant family and friends (Olsen & Kraft, 2009). And, although many social network users may have hundreds of online “friends,” studies show that they have regular contact with only a select few.

Social network site users have identified key aspects that help to explain why these sites are so popular. First, users appreciate the dynamic, social nature of social network sites where there is always something new each time you login. Users can reach out and contact many people with little effort, and keep track of what’s going on with others very quickly. Those with physical or social barriers find social network sites a valuable option that helps to lessen feelings of isolation (Olsen & Kraft, 2009). And,

users can choose how active they want to be, and do not feel obligated to participate more than they wish (Patterson, 2010). Some fear that social network use may be detrimental to users. Privacy issues and over-dependence on social networks as a primary socialization means have gained much attention in the past year (Olsen & Kraft, 2009).

Social network theory has come to the forefront in recent years with the increased use and pervasiveness of the Internet and social network sites like Facebook and Twitter. Social network theory views individuals as nodes within a network, and their relationships as ties that form relationships between individuals. One theory of particular interest from the field of social network theory is Granovetter's Strength of Weak Ties Theory, which describes the spread of information within social networks, and the value put on the strength of relationships (Granovetter, 1973). Granovetter suggests that within a social network, individuals have few strong ties, persons with whom they communicate regularly and intimately, but a large number of weak ties, persons connected through a series of bridges with whom they may have very little direct contact. The Weak Ties theory contends that strong ties require a great amount of time, emotional investment, and intimacy, and, as a result, information garnered from this relationship may be redundant, less novel, and not as valuable given this investment. Weaker ties require less time and investment to cultivate and maintain, while exposing an individual to a greater amount of information from a wide variety of resources.

### Internet and Health

Health and wellness information has never been more accessible (Colineau & Paris, 2010). Patients who have barriers to traditional, onsite health information, such as a

physician, clinic or library, can find information online at any time from anywhere (O'Grady, 2008b; Quin et al., 2010). The traditional healthcare consumer has become a virtual patient, and most often uses the Internet to find and share information about his or her own condition (Colineau & Paris, 2010; O'Grady, 2008b). Dr. Roni Zeiger, Google Chief Health Strategist, states that on any given day more people are posing health questions to Google than to their own physician (E. Cohen, 2010). Consequently, people report that they get more health information online than face-to-face (Colineau & Paris, 2010). In June 2010, 81% of all Internet users reported they do something health-related online less once a week. Demographically, health information seekers tend to be female, college educated, and have home broadband access (Fox, 2010). And, although a smaller fraction of seniors use the Internet, they use the Internet more often than 18- to 24 year olds to find health information (Seeman, 2008). Not surprisingly, people with more health concerns use the Internet for health reasons, with men more likely to look for information, and women looking for support and encouragement (Bunde et al., 2006; Im et al., 2007). And, as mobile devices become more prolific, 17% of all cell phone owners, and 29% of 18 to 29 year olds, have reported searching for health information on their phone (E. Cohen, 2010).

The Internet access gap, although shrinking considerably in recent years, has spawned another phenomenon, the online health information gap (Fox, 2010). This double-divide affect hits especially hard in rural areas where Internet access may be limited, and onsite healthcare access is unavailable (Chou et al., 2009). Studies shows, however, that when those in rural areas have Internet access available, they are more

likely to use the Internet to gain health information than their urban counterpart (Quin et al., 2010).

Chronic Disease and Internet Use. In the U.S., people with chronic illness are online less (62%) than their healthy counterparts (81%) (Fox, 2010; Miller, 2010). These numbers, however, do not reveal if this is due to a lack of Internet access or a lack of awareness or desire. Studies do show that 60% of Internet users with chronic illness are online on any given day, while 74% of healthy Internet users are online (Fox, 2010). However, those with chronic illness are using the Internet to find health information more often than healthy users (Fox, 2010; P. K. H. Mo & Coulson, 2010).

Internet use by those with chronic illness shows usage habits and trends that differentiate them from healthy users. More Internet users with chronic illness, one in five, create online health content — post comments, questions or information. Users with chronic illness are more likely to communicate online, with 8% participating in online discussions regarding specific health problems (Fox, 2010). Those with chronic illness are more likely to access user-generated health content such as blogs or reviews, and, similarly, are much more likely than healthy users to share what they know or experience with others (Fox, 2010; Miller, 2010). Those with chronic illness, unlike their healthy counterparts, are looking for information about a specific disease, and tend to go to trusted sites rather than relying on search engines to find answers (Fox, 2010; Miller, 2010).

Online Disease-Related Information. Studies show that most people consider the Internet as a “good starting point” to gather health information. And, for those with chronic illness, the Internet has become a critical tool for filling their health information needs. For those with Internet access, it is a convenient, always available resource, and provides anonymity, when desired, when medical conditions are too personal or embarrassing to discuss in person (Colineau & Paris, 2010). For those with chronic illness, the Internet is not seen as a substitute, but rather an adjunct to the information they receive from their physician (Colineau & Paris, 2010; Fox, 2010). Many look for pertinent disease-specific information online before and after office visits, while still interacting with their physician about more complex issues and to affirm or confirm information they gained online (Atreja et al., 2005; Colineau & Paris, 2010; Fox, 2007).

Health information can be found in a variety of formats and contexts. Some websites are strictly information depots while others provide support for users. Many sites, such as WebMD (<http://webmd.com>), provide information on a wide array of health topics while other are more illness-specific. And, some sites require online membership and promote relationships among members, while others allow anonymity for users (Colineau & Paris, 2010).

Health professionals, hospitals, clinics, organizations and corporations, currently dominate the online information mix (Fox, 2010). Even in social network realm, the American Cancer Society, for example, has over 250,000 Facebook (2010) “likes” and over 200,000 Twitter followers (2011). In recent years, however, “patient opinion leaders” have emerged in many disease areas. Social media tools have allowed patients to

create and share information, thereby joining the information mix. By amassing a large following, patient opinion leaders can create great presence in the disease-specific circles, and influence the decisions and behaviors of other patients, organizations and corporations (Sarasohn-Kahn, 2008).

Online health information-seeking behavior reflects much of the same processes proposed in Transformative Learning Theory (O'Grady et al., 2008). Patients “leverage” multiple sites, an average of five per scenario, to discover new information and confirm what is found, and to reassess and reconfirm their own knowledge, beliefs and perspectives. In this sense, they rely on the “collective wisdom” of the Internet to provide accurate and useful information (Colineau & Paris, 2010; Sarasohn-Kahn, 2008). In addition, online health research appears to be episodic with users looking for pertinent information on a need to know basis (Fox, 2010).

### Online Health Communities

In the same way the Internet evolved from Web 1.0 to 2.0, the introduction of social media tools has created Health 2.0 (Colineau & Paris, 2010; Fox, 2010). Health 2.0 is a product of the “fit” between patients need for greater interaction and support, and the technological capabilities of the Internet (G. J. Johnson & Ambrose, 2006). The new Health 2.0 landscape promotes greater interaction and participation, and allows individuals to seek out others with similar medical issues, and form disease-specific communities (Colineau & Paris, 2010). Internet support groups were seen in the early days of the Internet, mainly in the form of anonymous forums, listservs, and bulletin boards, but they lacked the interactivity and creativity that today’s social media tools

provide (Chou et al., 2009). While online support groups still exist today, many have evolved into online communities. Online communities are distinct Internet sites that encompass characteristics and features of both traditional online support groups and social network site. An online community is a virtual community whose members share a common interest, problem, or illness, as the case may be. As with social network sites, online communities employ a variety of social applications, including video and live chats, but the majority of interactions occur in public discussion areas or via member-to-member email (Chou et al., 2009). Unlike the larger, mainstream social network site, online community members tend to be strangers, initially, although this does not preclude the development or continuation of offline relationships (Chou et al., 2009; Colineau & Paris, 2010). People join online health communities, not primarily as a way to socialize, as with other social network site, but for the specific purpose of finding social support regarding their illness or condition (Colineau & Paris, 2010).

Statistics on online support groups and online health communities are fairly limited and difficult to compare. In 2007, 4.6% of Internet users participated in some sort of online support group, up from 3.9% in 2005. By 2010, 8% of those with chronic illness reported to participate in an online discussion or group regarding health (Fox, 2010). Demographically, those with chronic illness who use online support groups are more likely women, single, more recently diagnosed, symptomatic, and in poorer health, physically and perceptively (P. K. Mo, Malik, & Coulson, 2009). More specifically, higher online support groups use is reported by those with diseases that are life



threatening, less common or well known, and stigmatizing (LaCoursiere, 2001; C. F. van Uden-Kraan et al., 2008).

Much of what is available in traditional face-to-face support groups is found in their online counterparts — but online support groups many additional benefits (McCormack & Coulson, 2009). Most obvious, online support groups offer the flexibility and access that offline groups just can't match. Online, patients control when and how much they participate, whereas offline groups dictate a specific time and place for meetings (Im et al., 2007; LaCoursiere, 2001; Quin et al., 2010; T. Sullivan et al., 2003; C. van Uden-Kraan et al., 2009; Winzelberg et al., 2003). This anytime-access to information and resources allows patients to receive more up-to-date information instantaneously (Im et al., 2007; McCormack & Coulson, 2009; O'Grady, 2008b; Patterson, 2010; Sarasohn-Kahn, 2008). In addition, physical barriers disappear online, and many with chronic illness who have limited mobility or are geographically isolated can participate (M. A. Lieberman & Goldstein, 2005; McCormack & Coulson, 2009; P. K. H. Mo & Coulson, 2010; Quin et al., 2010; C. van Uden-Kraan et al., 2009). Online support groups allow more access and opportunities for patients to meet “patients like me” (O'Grady, 2008b). Some patients find it easier to discuss personal, sometimes embarrassing online, without face-to-face interaction (Im et al., 2007; McCormack & Coulson, 2009). In addition, asynchronous communication methods used in online support groups allow participants time to formulate questions and responses, and minimize the negative affects dominating or distracting members have in face-to-face support groups (Lawrence, 2002). And, while participation in face-to-face support groups

remains low, a recent survey of 92 lung cancer patients at the Mayo Clinic revealed that 21% indicated interest in a face-to-face support group, while 71% preferred an online option. Similar results have been found within other disease areas (Quin et al., 2010).

For those with chronic illness, online support groups can be a compliment, or an alternative to traditional face-to-face support groups (Till, 2003). Some participants report very good offline support for their illness, and simply choose to take advantage of all support available (Bunde et al., 2006). But for many, it may be the only option. People with chronic illness participate in online support groups for many of the same reasons they attend face-to-face support groups, namely to access much needed social support from those who share the same experiences (Colineau & Paris, 2010; Im et al., 2007; G. J. Johnson & Ambrose, 2006; Miller, 2010; Sarasohn-Kahn, 2008; Shirky, 2008; C. van Uden-Kraan et al., 2009). Online support groups, however, draw those who may feel isolated, either geographically or socially, and do not have access to other with the same illness (Im et al., 2007; P. K. H. Mo & Coulson, 2010; C. F. van Uden-Kraan et al., 2008). Similarly, many find that the local health community cannot meet all of their information and support needs (G. J. Johnson & Ambrose, 2006).

Johnson (2010) proposes that that a successful online health community needs four elements — people, purpose, protocols and technology. People create the sense of community, and people value that sense of community, and, ultimately, will claim the community as their own (Colineau & Paris, 2010; Im et al., 2007; McCormack & Coulson, 2009; C. F. van Uden-Kraan et al., 2008). Online health communities sponsored by large, national organizations or corporations do not foster that needed sense of

community, as many participants are leery of their motives and privacy practices (Im et al., 2007). Members value groups in which leadership is shared, with longer-term members taking on the responsibility to welcome and assist new members (Im et al., 2007; Levine, 2007; M. A. Lieberman & Goldstein, 2005; Till, 2003). Of course, building a community takes time, and initially, members view each other as strangers (Barak et al., 2008; O'Grady, 2008b; Quin et al., 2010; C. van Uden-Kraan et al., 2009). But, over time, anonymity decreases, and intimacy groups as members view each other as peers, and even “friends” (Colineau & Paris, 2010; Im et al., 2007). Groups that fail to stick to their purpose, and do not strive to keep information and resources current and relevant have less chance for success (C. F. van Uden-Kraan et al., 2008). In addition, communities that do not adhere to established protocols, whether due to a lack of established guidelines and practices, or ineffective enforcement of policies. And, finally, successful online health communities offer a wide range of social media tools to facilitate communication and information sharing among members. Steps must be taken to ensure that such tools are accessible and easy to use for all members (O'Grady, 2008b).

While successful online health communities encourage and appreciate active participation from all members, it cannot be demanded. As in any group setting, communication styles differ from member to member. In online groups, however, these differences, along with online communication patterns, present specific challenges. In online discourse, nonverbal cues are nonexistent. Lack of feedback may be negatively interpreted as snubbing or apathy, rather than attributing such silences to fear, reluctance or, simply, that nobody has a comment or answer (Lawrence, 2002). Passive members in

online communities, known as lurkers, tend to read information and postings from others without commenting. It is estimated that for every one active community member there may be as many as 20 lurking — some estimate this ratio may be as much as 100 to 1 (M. A. Lieberman & Goldstein, 2005; O'Grady, 2008b; C. van Uden-Kraan et al., 2008). But, lurkers are no less valued than active members within the online health communities, and, indeed, do report receiving benefits as community members. Many lurkers, after their comfort level increases, do become more actively involved in the community.

Online Social Support. Online social support is defined as the cognitive, perceptual, and transactional process of initiating, participating in and developing interactions via the Internet to seek beneficial health outcomes in healthcare status, perceived health, or psychosocial well-being (LaCoursiere, 2001). All three types of social support can be exchanged online (Olsen & Kraft, 2009). And, many studies report that online support group members perceive and/or receive social support through participation (Bunde et al., 2006; Chou et al., 2009; Colineau & Paris, 2010; Hill et al., 2006; Im et al., 2007; M. A. Lieberman & Goldstein, 2005; McCormack & Coulson, 2009; P. K. H. Mo & Coulson, 2010). Numerous studies have dissected the kinds of support exchanges seen in online support groups, but only recently has research begun to assess the effectiveness of online social support.

Informational social support, the exchange of illness information and experiences, is reported to be the primary reason those with chronic illness engage in online support groups (Bunde et al., 2006; G. J. Johnson & Ambrose, 2006; McCormack & Coulson, 2009; O'Grady et al., 2008). So, not surprisingly, informational support is shown to be

most frequently exchanged among group members (Civan & Pratt, 2007; Coulson, 2005; Im et al., 2007; M. A. Lieberman & Goldstein, 2005; McCormack & Coulson, 2009; Olsen & Kraft, 2009; Sarasohn-Kahn, 2008; CF van Uden-Kraan et al., 2009).

Information may be found within the exchange itself, or may be a reference to an external source (Civan & Pratt, 2007). Personal experiences, such as tips, advice on treatments and medications, are also considered informational support (Colineau & Paris, 2010; Miller, 2010; P. K. H. Mo & Coulson, 2010; O'Grady et al., 2008; Sarasohn-Kahn, 2008; Seeman, 2008; CF van Uden-Kraan et al., 2009).

Studies show that online support group members also want emotional support, and interpersonal connections with others (Im et al., 2007). Emotional support is communicated as gestures of empathy, reassurance, encouragement, appreciation, and optimism (Civan & Pratt, 2007; Colineau & Paris, 2010; Coulson, 2005; Im et al., 2007; M. A. Lieberman & Goldstein, 2005; McCormack & Coulson, 2009; Sarasohn-Kahn, 2008). Active constructive responding, reacting enthusiastically to good news, is gesture seen as especially positive and supportive with chronic illness communities (Olsen & Kraft, 2009).

Exchanges of instrumental support are seen in online support groups, but to a much lesser extent (Civan & Pratt, 2007). Most online support group members do not live in close proximity to each other, and, therefore, there are far fewer opportunities to offer or accept instrumental support. Instrumental support online may consist of offering assistance with projects, or helping with medical expenses.

While research does suggest that social support may have a positive affect on physical health status, there is little evidence that online support groups improve physical health status to any greater extent than other social support activities (Civan & Pratt, 2007; Colineau & Paris, 2010; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; JH Frost & Massagli, 2008; Olsen & Kraft, 2009). However, many psychological and psychosocial benefits have been reported by online support group members, and perhaps to a greater degree than seen in traditional support groups. A study of 372 cancer patients reported that social support received in an online support group resulted in decreased stress, depression, loneliness and anxiety, and increase adaptive coping abilities (Beaudoin & Tao, 2007). Other studies have reported increased feelings of empowerment, increased understanding and sense of knowledge of the disease (H. S. Campbell et al., 2004; C. van Uden-Kraan et al., 2009), increased use of positive coping strategies (P. K. H. Mo & Coulson, 2008), and increased perceptions of emotional support (C. F. van Uden-Kraan et al., 2008). Active participation in online support groups in itself can contribute social support perceptions. Offering support to others, and receiving genuine gestures of thanks and gratitude can be empowering. In addition, the act of writing, as one posts comments and experiences in online support groups, can be empowering, even cathartic for some, as a avenue to organize and clarify knowledge, thoughts and feelings (Barak et al., 2008).

Misinformation. Patients and medical professional alike express concern regarding the accuracy and intent of health information found online. Physicians are regularly confronted with information, and misinformation, patients find online (Esquivel

et al., 2006). Those with low health literacy may be especially susceptible to misleading or unfounded information (O'Grady et al., 2008). However, there is a vast amount of evidence showing that most information exchanged in online health communities is not damaging, and online support groups do not perpetuate misinformation (Esquivel et al., 2006; JH Frost & Massagli, 2008). In fact, only 2% of Internet users with chronic illness reported being harmed by information they found online (Fox, 2010; Miller, 2010). The low levels of misinformation, and therefore, low potential for harm reported in online health communities, is due to the collective wisdom of groups. Online communities are amazingly self-correcting. When medical statements posed by members are incorrect, other members do not hesitate to correct or criticize, and do so quickly. Bad information does not stay “up” for long, and is driven out, sometimes in a matter of hours (Esquivel et al., 2006; Sarasohn-Kahn, 2008; C. van Uden-Kraan et al., 2009).

### Inflammatory Bowel Disease (IBD)

This section will define IBD describe its physical and psychological aspects, describe the impacts of social support, illness knowledge, and illness representations on HRQOL of those with IBD, and discuss how the Internet can provide access to social support and illness knowledge for those with IBD.

Inflammatory Bowel Disease is the term used to describe two similar, yet distinct, inflammatory disorders of the gastrointestinal tract, Crohn's disease and ulcerative colitis (Blank & Switzer, 2006; Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Hall et al., 2005; Verma et al., 2001). Inflammatory bowel disease is an incurable

condition characterized by unpredictable periods of relapse and remission (Blank & Switzer, 2006; Francesc Casellas et al., 2002; Hall et al., 2005; Verma et al., 2001). Although the cause of IBD is unknown, research is leaning towards a combination of genetic, pathogenic and environmental factors contributing to the cause. Inflammatory bowel disease is considered an autoimmune disease in which the body's immune system reacts abnormally to gastrointestinal tissues to set off a ongoing cycle of inflammation (Casati et al., 2000; Crohn's and Colitis Foundation of America, 2011). In lieu of a cure, the goal in the medical management of IBD is to induce and maintain clinical remission, reduce inflammation, and control nutritional deficiencies and symptoms (Blank & Switzer, 2006; Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Hall et al., 2005).

Hard numbers for prevalence and incidence of IBD are hard to come by as many with IBD are misdiagnosed, and some go undiagnosed for years (Curtis, 2005). In 2005 an estimated 1.4 million Americans were diagnosed with IBD, up from an estimated 1.1 million in 2000. Approximately 30,000 new cases of IBD are diagnosed every year in the U.S. Incidence of ulcerative colitis exceeds that of Crohn's disease by a ratio of about 2 to 1 (Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Drossman et al., 1991; Verissimo, 2008). Onset of IBD, like many chronic diseases, is more often seen in young adulthood, between the ages of 20 and 40, with late teens/early twenties being prime years of onset. Inflammatory bowel disease in children is a growing demographic with ten percent of those with IBD under the age of 18. Inflammatory bowel disease affects men and women equally, but is seen more commonly in people of Jewish and



eastern European descent, and in colder climates. One-fifth of those with IBD have a family member with the disease, evidence of the emerging role genetics play in IBD incidence (Crohn's and Colitis Foundation of America, 2011).

### Physical Aspects of Inflammatory Bowel Disease

Inflammatory bowel disease is a physically disabling disease that can have a severe impact on physical, psychological and social well-being (Hall et al., 2005). Symptoms of Crohn's disease and ulcerative colitis are similar and it is sometimes difficult to make a definite diagnosis of one or the other. In ulcerative colitis, inflammation is confined to the colon with only the surface mucosa affected. In Crohn's disease, the entire gastrointestinal tract can be affected, and inflammation can penetrate through the walls of the intestines (Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Krause, 2003). In addition, Crohn's disease many times involves a variety of extra-intestinal complications that add to morbidity and difficulty in disease management. Up to 20% of those with Crohn's disease experience intestinal obstructions, abscesses, fistula, infections, arthritis, skin and eye infections, and liver dysfunction (Crohn's and Colitis Foundation of America, 2011; Sainsbury & Heatley, 2005; Vallis & Leddin, 2004). In some cases, toxic megacolon, or bowel rupture, can be a life-threatening result of IBD.

Symptoms of IBD vary from person to person, both in incidence and severity. Classic symptoms include mild to incapacitating abdominal pain, weight loss, chronic diarrhea, anorexia, joint pain, rectal bleeding, anemia, and fatigue (Blank & Switzer,

2006; Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Rogala et al., 2008; Sewitch et al., 2001). Fatigue, a result of the inflammatory process, anemia and some medications, is reported as one of the greatest, and many times unseen or overlooked concerns of those with IBD (Casati et al., 2000; Sainsbury & Heatley, 2005).

As there is no cure for IBD, treatment is palliative with reducing symptoms and inflammation as the primary goals. Approximately 25 to 50% of those with IBD relapse annually, and, therefore, most will stay on some sort of medication regimen for life (Curtis, 2005; Krause, 2003). When medications fail to control symptoms or induce remission, surgery to remove the diseased portions of the intestine is the only option. Up to 30% of those with ulcerative colitis will have surgery, while 70 to 80% of those with Crohn's disease will have at least one surgery in their lifetimes (Crohn's and Colitis Foundation of America, 2011; Moskovitz et al., 2000). An estimated 20 to 30% of those with Crohn's disease will have multiple surgeries; of these, however, up to 85% will have a recurrence of symptoms within three years (Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Drossman, 1995). Those with ulcerative colitis have the option of a total colectomy, or the removal of the entire colon. Colon removal requires placement of an ostomy, a small opening in the abdomen with an attached bag to collect waste. And, while many times an ostomy results in a pseudo-cure for those with ulcerative colitis, Crohn's disease patients with an ostomy more than likely continue to experience symptoms and relapse of the disease (Crohn's and Colitis Foundation of America, 2011; Curtis, 2005; Drossman, 1995).

Psychological Factors in  
Inflammatory Bowel Disease

The psychological distress secondary to the physiological symptoms and chronicity of IBD is an often overlooked, and sometimes equally debilitating aspect of IBD (Blank & Switzer, 2006; Casati et al., 2000; Drossman, 1995; Hall et al., 2005; Sewitch et al., 2001). Increased disease activity, both actual and perceived, is the most important indicator of increased psychological distress in those with IBD (Curtis, 2005; Drossman, 1995; Hall et al., 2005; Verissimo, 2008). But, as in other chronic illnesses, other factors play critical roles in contributing to emotional and social well-being. Stress can play a powerful role in the progression and management of most chronic illnesses (Sainsbury & Heatley, 2005). But, in IBD, stress can influence some physiological processes integral to proper gastrointestinal functioning, such as motility, immune function, and contribute to disease flare-ups and complications (Drossman, 1995; Sainsbury & Heatley, 2005; Sewitch et al., 2001). The uncertainty, unpredictability and often-embarrassing nature of IBD also contribute to decreased psychological well-being (Casati et al., 2000; Dorrian & Dempster, 2009; Hall et al., 2005; Rogala et al., 2008). Many with IBD experience a loss of independence, as they must restrict normal activities during times of relapse (Dorrian & Dempster, 2009; Hall et al., 2005). But, because of the unpredictable nature of IBD, many impose such social restrictions even during times of relative remission for fear of sudden onset of uncontrollable symptoms (Casati et al., 2000; Hall et al., 2005; Rogala et al., 2008). Treatments for IBD can also contribute to decreases psychological well-being. Surgery, especially ostomy placement, and some medications, such as corticosteroids, can have devastating affects on emotional status,

and body image (Casati et al., 2000; Dorrian & Dempster, 2009; Drossman, 1995; Hall et al., 2005; Rogala et al., 2008).

In the early days of IBD, the medical community focused on attributing the cause of IBD to psychological deficiencies of the patient. As recently as the 1970's, a common etiological theories ranged from having a "controlling mother" to fear of failure (Drossman, 1986). As a result, many with IBD believed they brought on the disease themselves, which contributed to the stress of the disease, and a vicious cycle ensued. More recent research all but disproved these theories, and have shown that people with IBD as "normal" as others with chronic illness (Drossman, 1995). Studies do reveal, however, that those with IBD are more psychologically distressed than the general population displaying higher levels of anxiety and depression, especially within the first year post-diagnosis (Curtis, 2005; Dorrian & Dempster, 2009; Drossman, 1995; Kurina, Goldacre, Yeates, & Gill, 2001). It is not known, however, whether this is a result of living with the disease, or a personality trait independent of the disease.

Studies reveal several common areas of concern for those with IBD that contribute to decreased psychological and psychosocial well-being. The lack of energy associate with chronic fatigue is the most often cited concern of those with IBD (Casati et al., 2000; Drossman et al., 1991; Hall et al., 2005; Moskovitz et al., 2000; Rogala et al., 2008). This lack of energy results a reduction of normal activities and feelings of inadequacy, "not keeping up" with friends and family, and a sense of loss potential (Hall et al., 2005; Rogala et al., 2008). Rogala (2008) found that those with IBD reported the need to reduce work and home activities three times more often compared to the general

population. This can lead to feelings of isolation, sometimes a physical reality, but many times emotionally induced (Casati et al., 2000; Hall et al., 2005; Moskovitz et al., 2000). The embarrassing, stigmatizing, and sometimes socially unacceptable nature of IBD can cause those with IBD to keep to themselves, even avoiding social and public gathering, for fear of unexpected symptoms or accidents (Hall et al., 2005; LaCoursiere, 2001; Lonardi, 2007; McCormack & Coulson, 2009). Many hide their disease and its effects even from family and friends and put on a “brave face” as to not illicit worry or attention (Hall et al., 2005). Inflammatory bowel disease patients also cite loss of control, fear of surgery and complications, poor body image, and lack of sufficient disease information as great concerns (Casati et al., 2000; Drossman et al., 1991; Hall et al., 2005; Moskovitz et al., 2000).

Medically, controlling disease activity continues to be the goal of IBD management. However, more attention is now focused on the psychological and psychosocial factors that contribute to well-being, and ultimately, to disease activity and outcomes. Without a cure, identification of sources of psychological distress, and appropriate strategies are needed to help those with IBD to better cope with their disease, and improve quality of life (Casati et al., 2000; Sewitch et al., 2001; Vallis & Leddin, 2004).

#### Inflammatory Bowel Disease and Health-Related Quality of Life

Most research agrees that HRQOL is impaired in those with IBD (F. Casellas et al., 2005; Hall et al., 2005; Rogala et al., 2008; Sainsbury & Heatley, 2005; Verma et al.,

2001). Janke (2005) found that even though they demonstrated lower HRQOL than the general population, most with IBD, 88.5%, reported satisfaction with their lives.

Decreased HRQOL isn't unique to IBD, however, as similar results are seen in people with other chronic conditions such as diabetes (Janke et al., 2005). Studies have shown that, in general, women, those with less education and lower socioeconomic means report lower HRQOL. These results are similar to that of the general population, and may reflect the effects of financial restrictions and limited access to adequate healthcare (Francesc Casellas et al., 2002; Sainsbury & Heatley, 2005). However, those with IBD are a heterogeneous group and HRQOL cannot be generalized (Sainsbury & Heatley, 2005). And, while some studies report lower HRQOL in those with Crohn's disease, others do not see diagnosis as a key determinate in HRQOL (Janke et al., 2005; Sainsbury & Heatley, 2005).

Disease activity is the factor most often studied in relation to HRQOL in IBD. Not surprisingly, those with greater and more severe disease activity report decreased HRQOL (Blank & Switzer, 2006; Casati et al., 2000; Francesc Casellas et al., 2002; Janke et al., 2005; Sainsbury & Heatley, 2005; Vallis & Leddin, 2004). Conversely, those with fewer and less frequent relapses, fewer hospitalizations and longer disease duration tend to report higher HRQOL (Dorrian & Dempster, 2009). But, questions exist as to the degree disease activity influences HRQOL (Verissimo, 2008). Physical symptoms and measurable disease indices do not always correlate to explain reported HRQOL in individuals with IBD (F Casellas, Vivancos, Sampedro, & Malagelada, 2005; Verissimo, 2008). Even those in remission with inactive disease report decreased HRQOL (Rogala et

al., 2008). It is apparent that perceived disease status can influence HRQOL as much, or even more than actual disease activity (Verissimo, 2008).

It has become apparent that disease activity alone is not the only predictor of HRQOL in those with IBD (Hall et al., 2005). Both the physical symptoms and psychological challenges presented earlier can all have an effect on HRQOL (Blank & Switzer, 2006; F. Casellas et al., 2005; Janke et al., 2005; Rogala et al., 2008; Vallis & Leddin, 2004). It is not known, however, to what extent emotional, cognitive, behavioral and social factors have in determining HRQOL and disease outcome (Vallis & Leddin, 2004). Therefore, HRQOL should have a critical role in the management of IBD (Sainsbury & Heatley, 2005).

Social Support in Inflammatory Bowel Disease. Although research is limited, several studies in recent years have focused on the availability and effects on social support for people with IBD. It has been suggested that social support can mitigate the psychological distress associated with IBD, and consequently, improve over health status and quality of life (F. Casellas et al., 2005; Moskovitz et al., 2000). Sewtich (2001) reported that patients who were more satisfied with social support available to them were less vulnerable to psychological distress when confronted with stressful situations. A study by Curtis (2005) revealed that IBD patients with higher disease activity reported a greater need for social support, and further, those with higher levels of social support report higher quality of life. Similarly, Vallis (2004) found that those who reported decreased functioning ability also reported less available and received social support.

Several other studies have also reported decreased psychological distress and increased HRQOL with access to adequate social support (Janke et al., 2005; Rogala et al., 2008).

The unique and challenging physical and psychological aspects of IBD sometimes make accessing social support difficult at times. A reluctance to socialize and the ongoing fatigue and lack of energy can make it difficult to cultivate and sustain a large social network (Sewitch et al., 2001). Indeed, those with IBD tend to have smaller social networks (Joachim, 2002; Sewitch et al., 2001). Those in remission, not surprisingly, report having larger social networks (Curtis, 2005). But, regardless of the social network size, most people with IBD report high levels of social support in their lives (Rogala et al., 2008; Sainsbury & Heatley, 2005; Sewitch et al., 2001). This may reflect the finding that an individual's perception of social support availability, knowing there is at least one person who can help, may be more important than social network size (Curtis, 2005; Drossman, 1995).

Still, the high incidence of psychological distress in people with IBD suggests that many do not receive, or have access to, adequate and beneficial social support (Curtis, 2005). Rogala (2008) found that those with IBD were less likely than the general population to report having someone who understands their problems. Further, 25% of those with high levels of disease activity reported they had nobody who understood their problems. Not surprisingly, social support among those with IBD was most beneficial when offered by someone who also had IBD (Curtis, 2005; Rogala et al., 2008; Sainsbury & Heatley, 2005; Sewitch et al., 2001). It is also suggested that similar demographics, such as socioeconomics, age, sex, geographical location and education, as well as disease



characteristics, such as diagnosis, duration of disease, concerns, treatments and complications, play a beneficial role in social support interactions (Curtis, 2005).

Illness Knowledge and Inflammatory Bowel Disease. As with other chronic illness, there appears to be a growing demand by patients for more detailed information about IBD (Verma et al., 2001). Research into IBD and illness knowledge, however, is scarce, and current findings regarding its affect on disease status and HRQOL is conflicting. Hall (2005) found that a small minority of individuals with IBD had knowledge of IBD prior to their own diagnosis. Gazzard (1987) found that only 35 of 85 study participants had read about their disease, reporting difficulty finding easy-to-understand information. Many studies reveal that even with demonstrated high level of sound IBD knowledge, many with IBD report a lack of information (Hall et al., 2005; Sainsbury & Heatley, 2005). In particular, many with IBD want specific, more personal information regarding the “control” of their disease, such as the role of diet and stress — questions that their physician likely cannot answer (Verma et al., 2001). Evidence as to the affects of illness knowledge on HRQOL are also mixed. Verma (2001) found that 64% of study participants reported being “well-informed” about their disease; however, 90% demonstrated impaired HRQOL. Similarly, Verma (2001) found no correlation between IBD knowledge and HRQOL. Some studies have even suggested that increased disease knowledge could negatively affect HRQOL, as more knowledge of the potential complications of IBD could cause fear, worry and depression (Janke et al., 2005). Dorrian (2009), however, found that high illness coherence and greater understanding of

IBD contributed to lower levels of psychological distress. In such cases, illness knowledge is shown to serve as a protective factor against psychological distress.

Illness Representations of Inflammatory Bowel Disease. As seen in Leventhal's model, how an individual perceives his or her illness plays a significant role in adjusting to disease (Dorrian & Dempster, 2009). In addition to the physical attributes of IBD, such as pain and disease activity, how patients cognitively, emotionally, and socially attribute their health status to their disease can have significant affects on adjustment to their disease and, ultimately, their quality of life.

Two studies have demonstrated the effect of illness representation on adjustment to IBD. Dorrian (2009), in a survey of 80 adults with IBD, identified two significant patterns of illness representation that have shown to negatively affect quality of life. First, disease expectations and fear of consequences was the most consistent variable to explain poor adjustment to IBD. The unpredictability and uncertainty of IBD, the potential seriousness of the disease, and the perceived lack of control of the disease translated to poorer quality of life. Second, those who try to attribute their disease, and its symptoms, to psychological causes were more likely to be psychologically distressed. In general, people are quick to attribute personal meaning to their experiences. Some with IBD misattribute inexplicable and uncontrollable symptoms, and, thus, contribute to the false belief that psychological factors, such as stress, cause IBD. Similarly, many misattribute symptoms not IBD-related to the disease itself, and many, in turn, misperceive the actual activity of the disease.

Krause (2003) examined the illness representations of members of a IBD self-help group over a one year period. Prior to the intervention, many members saw their disease as a serious handicap, and expressed high levels of depression, anxiety and fear regarding their disease. As a result of the support and information gained in the group, members displayed a narrower, more “normalized” view of their disease. This change in illness perception was expressed as “feeling better in spite of the disease.” Members transformed their self-image from that of a “sick” person, to someone who may need special care from time to time. Members were able to more accurately recognize actual limitations imposed by the disease, decrease feelings of self-demand and lack of control, and, consequently remove unnecessary restrictions on their activities. Members demonstrated more autonomy, disease acceptance and adjustment, and reported increased quality of life.

*Coping Strategies in Inflammatory Bowel Disease.* As with other influences on HRQOL in IBD, research focused on coping strategies is limited and inconclusive. Dorrian (2009) found that coping was not a significant predictor of illness adjustment in IBD. However, emotion-focused coping strategies were shown to decrease HRQOL. Two other studies reported that positive coping strategies did, indeed, directly influence health outcomes and contributed to increased HRQOL (Curtis, 2005; Sainsbury & Heatley, 2005). Hall (2005) suggests that problem-based coping strategies, such as exercise, seeking information and support, and controlling diet, contributed to increased HRQOL. Some studies suggest, however, that those with IBD who report higher HRQOL do not use “more” adaptive coping behaviors, but instead, use “less” maladaptive coping behaviors, such as self-blame, avoidance and pessimism (Moskovitz et al., 2000; Rogala

et al., 2008). Moskovitz (2000) also found, however, that maladaptive coping behaviors are modifiable through social support received through support group participation.

### The Internet and Inflammatory Bowel Disease

There is very little research regarding Internet use among those with IBD. As presented earlier, however, there is ample evidence that the Internet can be a valuable source of social support, both informational and emotion, for those with chronic illness. There are many similarities among those with chronic illness that would allow assumptions that those with IBD would have equally beneficial success. IBD, however, presents many unique challenges that would suggest the Internet might be even more beneficial for this population. The lower prevalence, stigmatizing and often embarrassing symptoms, and the unpredictability of IBD lends well to the accessible, anonymous and social nature of the Internet. The Internet offers many opportunities for those with IBD to gain vital illness knowledge and support from others who experience the same disease.

Online Inflammatory Bowel Disease-Related Knowledge. The Internet is a popular source of disease-related information for those with IBD, and this trend will only increase in the future (Siegel, 2007). There is much consternation from the IBD health community that IBD-specific information found online is incorrect, misleading, and not presented at a level most with IBD can understand (Promislow, Walker, Taheri, & Bernstein, 2010; Siegel, 2007). A study by van Der Marel (2009) examined 76 websites, institutional, pharmaceutical, commercial, charitable, support, and alternative medicine that provide IBD-specific information. Results revealed that only 43% provided

information deemed accurate and useful for IBD patients, while 57% was judged fair to poor. Further, much of the information presented was much too difficult for a significant portion of IBD patients to understand. Promislow (2010) found that the “best” IBD websites, those that best meet the patients’ information needs, are the Crohn’s and Colitis Foundation of America (<http://ccfa.org>), About.com (<http://about.com>), Health Central (<http://healthcentral.com>), and WebMD (<http://webmd.com>). It is suggested that although many websites provide IBD-related information, many lack information that patients themselves find important. Further, websites would benefit by clearly identifying sources of the information presented, and dating information updates. And, finally, this study, too, recommended that information aimed at the IBD patient population be better organized, and presented at lower reading level. Some have suggested that the IBD medical community do more to guide patients to the most reliable websites (Siegel, 2007).

There is, perhaps, only one study that focuses specifically on the Internet as a source for disease-related information for those with IBD. Cima (2007) surveyed 168 patients at the Mayo Clinic’s Gastroenterology clinic to assess Internet use to gather IBD-specific information. Eighty-one percent of the respondents had home Internet access, a rate slightly about the national average, and a promising finding. Results showed that over half used the Internet to gather IBD-specific information, more often than printed literature was used. Compared to cancer patients, Internet use for disease-related information may be two times greater, possibly highlighting the fact that the IBD population is, on average, a young demographic (Basch, Thaler, Shi, Yakren, & Schrag,

2004; Chen & Siu, 2001). In line with general population, Internet use decreases with age and education level, but still 37.5% of senior IBD patients used the Internet to find IBD-specific information. Those surveyed preferred and trusted non-commercial sites, most commonly organizational or institutional, and chose websites that were easy to use.

Online Social Support for Inflammatory Bowel Disease. There are no studies to date that focus specifically on the Internet as a social support source for those with IBD. The Internet is littered with disease-specific websites that offer support for those with chronic illness, and IBD is no exception. A cursory Google search found several well-known, popular IBD support websites administered and/or sponsored by pharmaceutical, commercial, charitable, and IBD patients themselves. Overall, the most popular, as evidenced by the membership and exchange volume, appear to be those website that are patient administered, IBD-specific, and presented in a social network format with high use of social media tools. Websites that are primarily information-driven, such as WebMD and HealingWell, do not show the high membership or exchange volume. Sites that do not provide a “community” atmosphere in which little information is known about the users also show lower user and volume numbers. Further, sites obviously sponsored by a commercial entity also have less traffic. And, while most sites also had a presence on Facebook and Twitter, only one provided Facebook integration, allowing users to login with their Facebook account.

### Inflammatory Bowel Disease in Montana

This final section will describe the current status of Internet use and availability in Montana, and education and support opportunities for those in Montana with IBD. The findings of two pilot studies that assessed the perceptions and experiences of those in Montana with IBD regarding educational and support opportunities in Montana will also be presented.

Montana has a population of 985,235 people, 0.3% of the U.S. population, inhabiting a territory of 145,552 square miles, with a population density of only 6.7 people per square mile ("State Fact Sheets: Montana," 2010). Montana's population is 65% rural, and the largest city has a population under 100,000 ("State Fact Sheets: Montana," 2010). And, while there are 63 hospitals in Montana, many still must travel hundreds of miles, many times out of state, to receive appropriate and adequate healthcare ("Rural Assistance Center: Montana State Resources," 2011). And, while those in rural areas feel an increased degree of isolation, even those living in urbanized areas of Montana experience a great deal of isolation. As compared to their urban counterparts in larger states, "big cities" in Montana are relatively small, and therefore, have fewer people affected with IBD, and less opportunities for education and support.

Not surprisingly, there is no published research specifically regarding the experiences of people in Montana with IBD, or in other rural areas in the US. There is, however, some information regarding the experiences of those with chronic illness who live in rural areas. Studies show that this population is challenged geographically and population-wise when it comes to healthcare in general. Those with chronic illness in

rural areas report access to healthcare services, and in particular, face-to-face information and social support is extremely limited or non-existent (S. Cudney, Sullivan, et al., 2005; Hill et al., 2006; M. Lieberman, 2007; Quin et al., 2010; Sarasohn-Kahn, 2008; Sherman et al., 2008; T. Sullivan et al., 2003; C. F. van Uden-Kraan et al., 2008). Many are challenged with traveling great distances, sometimes in inclement weather, while also incurring the financial burden associated with travel. Patients also describe extreme feelings of loneliness and isolation, a result of both the physical isolation, and, often seen with lesser-known illnesses, limited access to others with similar conditions (S. Cudney, Sullivan, et al., 2005; Hill et al., 2006; Im et al., 2007; M. Lieberman, 2007; Quin et al., 2010; Sarasohn-Kahn, 2008; T. Sullivan et al., 2003).

Many have suggested that increased use of the Internet could help to mitigate the geographic barriers and alleviate the isolation those with chronic illness in rural areas experience (McCormack & Coulson, 2009; P. K. H. Mo & Coulson, 2008; O'Grady, 2008b; Quin et al., 2010; Sherman et al., 2008; CF van Uden-Kraan et al., 2009).

Although nationwide it is estimated that approximately 50% of the rural population have home Internet access, as of June 2010, a reported 73.6% of Montanans have Internet access, suggesting that a higher proportion of rural Montanans have Internet access (Quin et al., 2010; "United States Internet and Facebook User Statistics," 2010).

There are few programs in the U.S. that specifically address the issues those in rural areas with chronic illness face using the power of the Internet. The Women to Women Project, an online support and health information network for rural women with chronic diseases, provides an online community for women with chronic illnesses to



meet, socialize, and gain information from other women with similar conditions (S. Cudney, Winters, Weinert, & Anderson, 2005; Hill et al., 2006; Clarann Weinert, 2005; C Weinert, Cudney, & Winters, 2005; Winters, Cudney, Sullivan, & Thuesen, 2006). The Women to Women Project focuses on the issues and impacts chronic disease has on rural women. Participants in the program reported high levels of isolation, limited contact with other with similar conditions, and frustration with the geographical challenges those in rural Montana experience. The women reported exchanging both informational and emotional support with other members, and expressed a sense of self-reliance through these exchanges (Clarann Weinert, 2005). Through this social support network, women have reported an increase in self-esteem and overall well-being (Hill et al., 2006). The project recently completed its third study phase, which included some 309 women in nine western states, with 39% residing in Montana. Participants represent a variety of chronic illness, with 39% reporting rheumatoid disorders, 21% neurologic disorders, and ten women reporting gastrointestinal disorders.

### Pilot Studies

To provide a foundation and gain insights into the needs and experiences of those with IBD in Montana, this researcher conducted two pilot studies (Nehasil, 2009a, 2009b). The purpose of each study was to describe the education and support opportunities available to people with IBD in Montana, and gather some statistical data on the demographics of this population. The first study, conducted in April 2009, six women were interviewed and the results analyzed using qualitative research methods. In the second study, conducted in the summer of 2009, ten people with IBD were

interviewed and the results similarly analyzed. Thirteen of the participants lived in “urbanized” areas of Montana, while three lived in rural locations. The premise of each study, that those with IBD in Montana experienced a lack of adequate and accessible support and educational opportunities, was validated. Eight main themes emerged as a result of the studies.

First, all 16 participants reported that the Internet was their number one source for IBD-specific information. It must be noted that all participants had Internet access, and all but one had access at home. Although many report that it was sometimes difficult to find information and much of what they found was confusing, as one participant stated, “It’s the only game in town.” Many expressed a desire to have one site with “everything in one place” with “local and regional resources.” But, using the Internet as a means of social support was not a highly used practice. Only one had ever interacted in an online IBD forum, although others had read through them to learn from others experiences. Many expressed their reluctance to “talk to strangers” about their disease. Most said that they would rather talk to people within their own community who had similar experiences living in Montana.

Second, all 16 participants reported that they had little or no contact with other people who had IBD. Sadly, each participant expressed the words, “lonely” or “loneliness” at some point during the interview. All expressed a strong desire to meet and share experiences with others who have IBD. Third, all participants reported that their main avenue for emotional support was their family. Although this is a heartwarming response, many went further to say that most often their family and friends don’t

understand their condition, and, at times, they feel they are a burden on others. Fourth, there was a unanimous desire on the part of the participants to help others with IBD. Many confessed that it would help they themselves share their experiences with others who need help.

Fifth, a majority of the participants reported that although they had a very positive relationship with their physician and received support and information from them, they didn't receive enough time or access to their physician. In addition, there was no additional education or support made available to them through their clinic or hospital. Sixth, many cited a lack of public awareness of IBD, its symptoms, cause, and how it affects the individual. Many felt this lack of awareness further contributed to their feelings of isolation. Seventh, many of the participants expressed deep frustration and disappointment with the Crohn's and Colitis Foundation of America (CCFA). Sadly, several had not even heard of CCFA. Most cited CCFA's lack of presence, or interest, in Montana, and hoped for even one CCFA-sponsored education or support event. Those familiar with the CCFA website were not impressed and described it as unorganized, not useful, and "usually the same old stuff."

Perhaps the most enlightening responses were those soliciting their education and support needs and desires. An overwhelming majority expressed a need for a local network to help those with IBD find others in their community. Although only one participant had ever attended a support group, most said they would be willing to try it. Several participants suggested a mentoring program in which people with IBD could be available to help others in need. Many hoped for more IBD-related activities such as

educational programs, fundraisers, public awareness events, and even informal gatherings. One especially poignant comment summed up the Montana IBD experience very well: “Location is becoming a minor part of it. There’s still the problem of finding and reaching people.” After learning of the proposed online IBD community, all 16 participants expressed enthusiasm and support for the idea. Most felt it would be an effective way for those with IBD in Montana to meet others online — and locally.

### Chapter Summary

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge. The results of this study will provide data to Montana physicians and other health professionals demonstrating the viability of using a Montana-specific, online support community for those in Montana with IBD, and potential benefits to their patients’ overall quality of life.

Chapter 2 presented review of the literature regarding chronic illness, IBD, and Internet use in relation to HRQOL. Components of HRQOL, namely social support, illness knowledge and illness representations, were also reviewed.

Chapter 3 will present information concerning the quantitative and qualitative methods that will be used to obtain information from participants in a Montana-specific,

online IBD support community regarding their assessments of and experiences within the community, and how their experiences affect their health-related quality of life.

## CHAPTER 3

## METHODOLOGY

Background and Purpose

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge. Research shows that access to social support can help mitigate the negative psychological effects of chronic illness, and positively influence health outcomes, ultimately improving the health-related quality of life of those affected (Colineau & Paris, 2010; Moskowitz et al., 2000; Shigaki et al., 2008). Additionally, interaction with others with the same chronic illness can provide opportunities to gain much needed illness-related knowledge (C. Campbell, 2001; Krause, 2003). Studies also suggest that patients will more likely participate in a disease-specific support or education activity when specifically recommended by their physician (Eakin & Strycker, 2001; Guidry et al., 1997; Sherman et al., 2008). The results of this study will provide Montana physicians and other health professionals' data demonstrating the viability of a Montana-specific, online support community for those in Montana with IBD, and potential benefits to their patients' overall quality of life. This chapter describes the participants, research design, instruments, and data analysis methods used in this study.

Health-related quality of life is a term used to explain how illness affects an individual when clinical indicators alone are insufficient (Blank & Switzer, 2006). It involves a person's emotional, social and physical well-being and his or her ability to perform tasks of every day living (Donald, 2001; Orley, Saxena, & WHOQOL Health Group, 1996; Pulman, 2010; Verma et al., 2001). Health-related quality of life is increasingly becoming a major factor in treatment and illness management plans. (Ferrans et al., 2005; Hall et al., 2005).

This study posed the following research questions regarding participation in a Montana-specific, online support community for people in Montana with IBD:

1. How do participants assess and describe their experiences within the online community?
2. How have their experiences impacted their HRQOL as exhibited through impacts on social support?
3. How have their experiences impacted their HRQOL as exhibited through impacts on illness knowledge?

#### Overview of the MontanasGotGuts Website

The MontanasGotGuts website (<http://montanasingotguts.org>), created and administered by the researcher in this study, launched in late 2011 (see Appendix B). The website was created not only to serve those in Montana with IBD, but also to serve as the focal point of this study. The website is a comprehensive online community and is closed to all but registered members. Each member creates an online profile with which to communicate and post within the community. The main sections of the website consist of

a discussion forum, IBD-related news feed, member blogs, an event calendar, multimedia galleries, and an interactive member map displaying the location of each member. The community also has a live chat feature and private messaging capabilities.

### Researcher Positionality and Reflexivity

Having lived with severe and highly complicated Crohn's disease for 30 years, I possess unique insights, attitudes, and, a very definite positionality as the researcher in this study. Without my positionality, this study would have been of little importance to me, and never would have been conducted. As the researcher, I was well aware of the potential bias I may bring to the study, whether during the interview process, or within the interpretation of the data. As someone who is also part of my study population, I can relate to many of their experiences, and at times, found myself comparing their experiences to my own. Great effort was taken as to not let my own experiences or comparisons negatively affect the interpretation of data or the outcomes of the study. A few of the study participants were also acquaintances, although none were considered to be "good friends." But, even so, as acquaintances whose paths crossed with mine in our small town or workplace, I was privy to additional information and observations of these participants. Some of this information did influence my interpretations of data received from those individuals, and contributed in positive ways to describing and understanding their entire experience with IBD.

### Rationale for Descriptive Study

Descriptive research is used to describe characteristics of a population or



phenomenon being studied. Descriptive studies also help to demonstrate associations and relationships between individuals and their environment (Gay, 1996). Descriptive studies describe the world as it exists, the “what is,” and allows researchers to compare these descriptions to “what we would like.” Descriptive studies cannot draw conclusions that show cause and effect, but they can allow researchers to see areas that need to be addressed. Descriptive research may use both quantitative and qualitative methodologies to gather data that best describes the phenomenon and its participants (Gay, 1996; Knupfer & McLellan, 2001). In this study, a self-report survey instrument was initially used to obtain demographic data, and data on how participants report experiences within the online community. Subsequently, qualitative research methods, using semi-structured interviews, were conducted to collect more insightful, narrative data not possible through the survey instrument. Qualitative methods allow the researcher to expand on data collected through the survey, and find out why participants responded as they did (Creswell, 2007). By using multiple methods of data collection, or triangulation, researchers may gain a much richer and more accurate description of the phenomenon at hand. In this study, questions similar in nature were presented in both the quantitative survey and the qualitative interview in an attempt to reinforce the accuracy of the data.

### Quantitative Phase

#### Participants

The population for this study consisted of members of an online support community for people in Montana with IBD. The MontanasGotGuts online community

garnered its membership via multiple avenues: emailing past study participants, emailing past IBD community event participants, posted announcements in medical offices and other public gathering venues, and word of mouth (see Appendix F). All members of the online community (a population of 40 at the start of this study) received a personal email from the researcher requesting their participation in the study (see Appendix C). The email contained a brief overview of the study, and what their participation would entail. Interested participants were instructed to reply to the email to receive a follow-up email with a link to the online survey. Those who did not reply were sent a second and final email again requesting their participation. This process continued until a sample size of ten participants was achieved.

This online community is targeted towards adult men and women who live in Montana and have been diagnosed with IBD, but it is possible that some members may not have diagnosed IBD. Evidence of diagnosis was based on each participant's declaration, as no medical proof was requested from the participants. Measures to minimize inclusion of those who do not have IBD will be discussed in the following sections. Similarly, as this is an online community, there is the possibility that individuals from outside Montana may attempt to join the online community. To minimize this occurrence, the website contains a geo-locating function to pinpoint the exact location of the user. The nature of this study did stipulate that each participant have access to the Internet and a computer, and have sufficient technical skills to navigate and communicate within the online community.

Although Montana is not known as an exceptionally diverse state, it was hoped

that the study sample would include participants from all areas of Montana, urban and rural, those with Crohn's disease and ulcerative colitis, men and women, and adults of all ages, socio-demographics and education levels. But, as the population of Montana is relatively small, the incidence of IBD in Montana is small, and the online community membership was low, the researcher was not able to purposefully select participants for the study. The final study sample consisted of eight women and two men with ages ranging from 20 to 66. Seven participants lived in or near Bozeman, one lived in Billings, and two lived in more rural areas of Western Montana. It was a well-educated group with eight participants having at least some college experience, and four with college degrees. All participants had high school degrees. Seven participants had Crohn's disease while three had ulcerative colitis. All of the participants had been diagnosed with IBD for at least three years so there were no newly diagnosed participants.

### Design and Procedure

For this study, a survey tool was developed to 1) collect demographic and website usage data, and 2) assess participants experiences and outcomes in the online community. SurveyGizmo (<http://surveygizmo.com>), an online survey tool, was used to collect this data. Survey questionnaires are sets of carefully designed questions given to a population to in order to gain descriptive and statistical information. They also allow various types of data to be collected in an objective and standardized format. Questionnaires are inexpensive, can be self-administered, anonymous, if necessary, and can reach a large group of people in a short period of time (Creswell, 2007). For studies that include a specific disease population, the use of disease-specific instruments, when available, is

preferred over generic tools to both increase participant acceptance of the tool, and to omit factors irrelevant to the population (Gugiu, Coryn, & Applegate, 2010; N. Johnson, 1998; Sherbourne, 1991). In addition to the survey, website administrative tools and Google Analytics provided were used to monitor and collect comprehensive member usage data.

### Instrument

To collect descriptive data, the researcher created an 20-item questionnaire specific to IBD and the specialized nature of online interventions (see Appendix D). The first section contained general demographic questions about the participant. The second section asked about general Internet usage as well as participants use of the online community. More specifically, questions asked which parts of the website were most helpful, and how this community compares to other sources of support and information. Questions in the third section asked about the participant's community participation experiences. These questions were based on findings in the literature review concerning the social domain of HRQOL, and how it is influenced by social support interactions and experiences. Social support and illness-related knowledge were measured by assessing empowering outcomes reported by participants. Empowerment encompasses a belief that patients are autonomous and have right and responsibility to access health information and make their own health-related decisions, and thus, can be an indicator of positive social support and illness-related knowledge experiences. Van Uden-Kraan (2002, 2008) identified seven constructs that describe empowering outcomes of online support groups for those with chronic illness. Several questions reflected these seven constructs.

- Feel better informed.
- Feel more confident in relationship with physician.
- Improved acceptance of the illness.
- Increased confidence in treatment.
- Increased optimism and control over the future.
- Enhanced self-esteem.
- Enhanced social well-being.

The final section of the survey asked four open-ended questions regarding their experiences within the online community. In some cases, responses to these four questions were explored further during the interview portion of the study.

The table of specifications (see Table 1) shows the survey questions reflected within each area of interest. The table also aligns the survey questions with the research questions posed by this study. The table of specifications helps to establish validity to the study.

Table 1

Table of Specifications Containing Survey and Interview Questions

	Survey Questions	Interview Questions	Research Questions
1. Social support	16e, f, i-n, 17-20	1, 2, 5, 9	3
2. Illness knowledge	16a-d, g, h, 17-20	1, 2, 6	2
3. Demographics	1-9		1
4. Internet/website use	10-15	1-4, 7, 8, 9	1

The survey included three questions to help ensure validity of the sample. First, when asked which disease they have, participants were provided space to fill in “other” if they did not have Crohn’s disease or ulcerative colitis. This step was taken to ensure that all participants had a diagnosis of IBD from a medical professional. As no participant selected “other” all in the study did have diagnosed IBD. Similarly, the survey asked each participant to “write-in” the city in which they live. This was done to further validate their location identified via geo-location methods within the website, and ensure all study participants lived in Montana. All participants indicated that they lived in city in Montana. And, finally, none of the survey respondents indicated that he or she was less than 18 years of age. The respondent would have been instantly disqualified and not allowed to complete the survey if that were the case.

The instrument was evaluated and reviewed by the researcher’s advisor and committee members to provide additional content validity. Face validity was established through pilot testing of the instrument. Two colleagues whom had participated in previous studies by this researcher, and also have IBD, served as testers of the instrument. Feedback from the testers was collected with respect to ease of use, time required to complete the survey, interpretation of questions, and overall impression of the instrument. The questions were perceived to be understandable and approved by the testers. The instrument and study protocol were approved by the Montana State University Institutional Review Board (IRB). A Request for Exemption form was submitted and approved by the IRB, as this study does not involve children less than 18 years of age, nor does it involve the use or disclosure of medical documents or records by

the participants.

The first page of the online survey contained a brief summary of the study and an informed consent checkbox. Checking the box indicated that the participant agreed to participate in the study, agreed to be interviewed, and agreed to have his or her information included in the study. Participants could not begin the survey until the checkbox was checked.

### Data Collection and Analysis

Descriptive statistics were used in the quantitative phase of the study. Descriptive research involves collecting data to answer questions about reality and how participants assess certain conditions, experiences and issues. Descriptive data is often obtained through surveys and questionnaires (Gay, 1996).

After the ten survey questionnaires were completed, data analysis was conducted using Dedoose, an online qualitative and mixed methods research tool. All data collected via SurveyGizmo were exported to a file and imported into Dedoose where they could be analyzed and prepared for presentation. Descriptive statistics in the form of percentages were used to report demographic data, website usage data, members' assessment and evaluation of the website, and members' assessment and evaluation of their experiences with respect to perceived social support, illness knowledge and health-related quality of life.

## Qualitative Phase

### Participants

All ten participants who agreed to participate in the study and completed the online survey completed the interview portion of the study. Upon completion of the online survey, each participant was immediately contacted via email to set up a time and place for the interview.

### Design and Procedure

The qualitative phase of the study involved a process of inquiry, occurring in a natural setting, and, subsequently, making sense of the information brought forth (Creswell, 2007). Small samples are appropriate for qualitative research, as purposeful samples provide more in-depth data than that obtained through quantitative research (Creswell, 2007; Patton, 2002). This phase was designed to identify themes to assist the researcher, and the Montana healthcare community, in understanding the experiences of those participating in the online community. More specifically, the qualitative phase of this study allowed the participants to elaborate on their experiences within the community, and provide details about their own social support and IBD-related knowledge as a result of engaging in the community.

Semi-structured interviews were conducted with the ten participants to gain additional insight into their psychological processes, perspectives and experiences (Hall et al., 2005). Semi-structured interviews allow for flexible probing of responses and issues that result from the quantitative phase, and can lead to more insightful and



meaningful data. Face-to-face interviews were conducted with five of the ten participants. However, as this study focused on a geographically diverse population from throughout Montana, five of the interviews were conducted via Skype and a telephone. All interviews were recorded on a laptop computer using Skype or GarageBand. Each interview was subsequently transcribed, verbatim, using a transcription service. Each participant was given the opportunity to review his or her transcript and offer feedback. None accepted this offer.

### Interview Protocols

The researcher utilized qualitative research methods, interviews and observations, to gather information not obtained from the questionnaire, and to provide more in depth explanations of survey responses. Using information obtained through the literature review, interview questions were developed to best address the research questions posed in the study (see Appendix E). To lend face and content validity, the interview questions were reviewed for accuracy and relevance to the purpose by the researcher's advisor and committee members. Pilot testing of the interview questions was conducted using the same two colleagues who tested the survey instrument. One additional question regarding the necessity for a Montana-only community was added as a result of this process. Table 1 shows the nine interview questions reflected within each area of interest, and aligned with the research questions posed in this study. Participants were asked the same questions in the same order to aid in comparison and the development of themes (Creswell, 2007). The researcher used follow-up questions to help explain and explore answers given by interviewees (Gay, 1996). And, as instrument reliability depends on the

reliability and validity of the researcher, the researcher attempted to use the same body language and demeanor with all participants (Creswell, 2007).

### Data Collection and Analysis

Qualitative analysis allows the researcher to develop richer and more detailed descriptions of the findings. In addition, qualitative data serve to verify and add meaning to the quantitative results.

All observation notes and transcribed interviews were organized using Dedoose. Additionally, activities of the sample participants within the online support were observed and recorded by the researcher to lend a deeper layer, and a degree of triangulation to the data (Krause, 2003). It should be noted that while the website administrator could observe all activities and communications throughout the website, only the activities and communications of people who agree to participate in the study were documented and used in the study. Through the use of coding, all qualitative data were thematically analyzed to determine issues of greatest importance to the participants, common experiences shared by the participants, and activities and practices that were common and potentially successful, or detrimental, to the participants. Significant statements that best describe and demonstrate participants' experiences were highlighted. Furthermore, data that is unique and does not "fit" into any established or emergent themes were noted if it appeared to provide an interesting perspective and additional insight to the study.

In the deductive phase, data was coded and sorted into categories in line with the goals and research questions put forth in the study. In the inductive phase, additional

themes and categories that emerged from the data were recognized. Linkages and relationships between the themes, the existing literature, and the researcher's observations were pulled together and presented in a meaningful conceptual scheme that comprehensively describes the participants' experiences.

To provide confidentiality and anonymity when reporting the findings pseudonyms were given for actual names, and any unique or personal information that might potentially be recognizable by others was altered or deleted from the final report (Creswell, 2007; Maxwell, 2005).

Member checking helps to establish validity of the data by allowing the participant to clarify or expand on information disclosed during the interview. Although each participant had the opportunity to review their interview transcript, none accepted this offer.

### Trustworthiness

Verification procedures were conducted throughout the collection and analysis of the data in order to ensure trustworthiness of data. Procedures that establish trustworthiness included maintaining participant confidentiality, recording field notes during the interviews, and transcribing interviews immediately, member checking, and triangulation. Data obtained through the interview process is value laden and often subjective (Creswell, 2007; Maxwell, 2005). The researcher remained aware of the potential for her bias throughout the process to ensure the integrity of the qualitative findings. This was especially crucial in this study as the researcher and the study participants were of the same population, and share many of the same characteristics and

experiences. And, although the researcher did ask probing questions throughout the interviews to verify accuracy of responses, much care was taken as to not lead or influence participants' responses.

### Chapter Summary

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assessed and described their experiences within the community, and how they reported that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge.

Chapter 3 presented information concerning the quantitative and qualitative methods that will be used to obtain information from participants in a Montana-specific, online IBD support community regarding their assessments of and experiences within the community, and how their experiences affect their health-related quality of life.

Chapter 4 will present the responses from the surveys and one-on-one interviews of the ten study participants. Data concerning participant demographics, Internet usage, and website analytics and usefulness will be presented along with data regarding community participation experiences. Themes that emerged from the interview data will also be presented.

## CHAPTER 4

## RESULTS

Introduction

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assessed and described their experiences within the community, and how they reported that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge. Research suggests that access to social support acquiring knowledge about one's disease may help mitigate the negative psychological effects of chronic illness, and positively influence health outcomes, ultimately improving the health-related quality of life of those affected (Colineau & Paris, 2010; Moskovitz et al., 2000; Shigaki et al., 2008).

This study posed the following research questions regarding participation in a Montana-specific, online support community for people in Montana with IBD:

1. How do participants assess and describe their experiences within the online community?
2. How have their experiences impacted their HRQOL as exhibited through impacts on social support?
3. How have their experiences impacted their HRQOL as exhibited through impacts on illness knowledge?

This chapter presents quantitative and qualitative findings obtained from surveys and interviews. Demographic characteristics of the participants are first presented, followed by select quantitative data obtained from participant surveys and website analytics. Next, a summary of significant themes that emerged through analysis of interview transcripts are presented. Quantitative data is used to augment and support relevant themes, as appropriate.

### Quantitative Data

Quantitative data was collected from the participants through an online survey prior to the interview. In addition to demographic data, the survey included questions regarding Internet and website use and usefulness, and community participation experiences. Objective website analytics are presented first, followed by a summary of survey responses.

### Demographic Factors

Table 2 displays select demographic factors of the ten participants. Eight women and two men, ages ranged from 20 to 66, participated in the study which involved completing a quantitative survey and a qualitative interview. Seven participants lived in or near Bozeman, one lived in Billings, and two lived in more rural areas of Western Montana. It is a well-educated group with eight participants having at least some college experience, and four with college degrees. All participants had high school degrees.

With respect to IBD, it was a somewhat veteran group with all participants diagnosed with IBD for at least three years. Moreover, six participants have had IBD for

at least six years, while for two it has been more than 20 years with IBD. Seven of the participants had Crohn's disease while three had ulcerative colitis. Six of the ten reported to be in good to very good health, while one described her health as poor. And while majority of participants stated that their health seldom affects their daily activities, two participants reported that their daily activities are affected most or every day.

Table 2

Participant Demographics (In alphabetical order by first name pseudonym)

Name	Gender	Age	Location	Education	IBD Dx	IBD Duration (years)	Health
Beth	F	31-40	Townsend	Some college	CD	5-10	Good
Cathy	F	60+	Stevensville	HS	CD	20+	Fair
Cindy	F	41-50	Bozeman	graduate degree	UC	10-20	Good
Jason	M	18-30	Billings	Graduate degree	UC	3-5	Good
Julie	F	41-50	Belgrade	College degree	CD	10-20	Fair
Kelly	F	18-30	Bozeman	Some college	CD	3-5	Good
Kyle	M	41-50	Bozeman	HS	CD	20+	Good
Melanie	F	31-40	Bozeman	graduate degree	UC	5-10	Good
Sandy	F	31-40	Bozeman	Some college	CD	10-20	Poor
Susan	F	31-40	Bozeman	Some college	CD	10-20	Fair

Note. IBD = Inflammatory Bowel Disease; CD = Crohn's disease; UC = ulcerative colitis;  
Dx = diagnosis

### Website Analytics

As of September 30, 2013, the MontanasGotGuts.org online community had 50 members. Google Analytics was used to objectively track website usage data. Table 3 presents six parameters commonly used by website administrators to describe website activity. During the one year time period of the study, the website averaged 48 total visits per month, 17 of which were unique visitors, amassing 271 pages views. An average of 5.63 pages were viewed per visit, with each visitor spending an average of just over seven minutes per visit. Each month, approximately 20 percent of all website sessions were from new visitors. This data illustrates that although website membership and traffic was low as compared to similar sites (see Appendix A), website visitation is maintaining a consistent average while continuing to attract new, unique visitors every month.

As seen in table 4, of the 3247 total page views on the website over the one year period, a vast majority, 28 percent, were views of the home page. The forum pages were the next highly viewed making up 18 percent of total views. It should be noted that the forum pages include the “IBD News & Research” postings as well as most communications between community members. Additionally, the most current forum posts, as well as the most current blog posts and event listings, are viewable on the home page of the website. This data helps to reinforce other data collected through the survey and interviews in which participants report that they value the news and information aspects of the website, and find these areas most useful.



Table 3

MontanasGotGuts.org Website Traffic by Month: October 2012 – September 30, 2013

Month	Unique Visitors	Total Visits <sup>1</sup>	Page Views <sup>2</sup>	Pages per Visit Avg.	Duration Avg. (m)	% New Visits
October 2012	21	75	593	7.91	12:08	13
November 2012	24	68	543	7.99	10:02	25
December 2012	13	24	140	5.83	7:42	21
January 2013	23	43	294	6.84	6:39	26
February 2013	25	78	510	6.54	10:28	19
March 2013	19	73	297	4.07	3:58	19
April 2013	8	25	74	2.96	2:47	16
May 2013	12	24	104	4.33	4:13	21
June 2013	15	33	159	4.82	7:29	27
July 2013	15	41	221	5.39	7:23	17
August 2013	23	56	229	4.09	4:29	27
September 2013	11	37	83	2.24	2:14	11
Monthly Avg.	17	48	271	5.63	7:19	20

<sup>1</sup>A visit is one visitor who arrives at the website and proceeds to browse, no matter how many times the same visitor may have been to the website.

<sup>2</sup>Once a visitor arrives at a website they will browse around on a few more pages. Each individual page a visitor views is tracked as a page view.

Table 4

MontanasGotGuts.org Website Activity per Page Content: October 1, 2012 – September 30, 2013

Page Content	Page Views
Home	923
Forums	538
Blogs	117
Member Profiles	75
Ask the Expert	64
Member Map	56

Note. Based on 3,247 total page views per year

### Internet Usage and Usefulness

All participants reported that they use the Internet daily, with nine of ten using it several times a day. This level of activity, however, was not reported regarding MontanasGotGuts.org website. Eight of ten participants visited the website less than weekly, and none visited more than once per week. A majority report website visits as between 10 and 30 minutes on average. Five of ten participants had never posted on the website, aside from the initial signup and profile information. And, half report posting less than once per week. It should be noted that at the time of the survey, the duration of participants' membership in the community ranged from one to six months.

However, table 5 reveals that when participants do visit the website, they value areas that provide information, news and research about IBD. All participants found the news and research section useful with six of ten finding it extremely useful. The forums were also identified as useful with all participants rating them somewhat to extremely useful. The events calendar garnered the most disparate reviews with eight of ten finding it very or extremely useful, while two found it not at all useful. The photo gallery and member map were shown to be least useful. Six of ten described the member maps as slightly or not at all useful, while five of ten viewed the photo gallery similarly.

Table 6 illustrates how participants rated the MontanasGotGuts.org website high as a resource for support and information as compared to other potential sources. The website ranked third, only behind their physician and nurse as a valuable source for support and IBD information and knowledge. Friends, family, and books and pamphlets received the lowest scores. It should be noted that the study participants were aware that

the researcher developed and administered the website, so the possibility of bias did exist. Additionally, respondents were asked to rank resources with respect to “support” and “information,” so it is not possible to distinguish whether results reflect attitudes towards either “support” or “information,” or a both.

Table 5

Usefulness of Website Areas (in order of usefulness combining extremely and very useful)

Area	Extremely useful (%)	Very useful (%)	Somewhat useful (%)	Slightly useful (%)	Not at all useful (%)
News & Research	60	30	10	0	0
Events Calendar	30	50	0	0	20
Forums	20	40	40	0	0
Member Blogs	10	50	30	0	10
Member Profiles	10	30	30	30	0
Private Messaging	10	30	30	20	10
Activity Stream	10	20	50	10	10
Photo Gallery	10	10	30	40	10
Online Chat	10	0	50	20	20
Member Maps	10	0	30	40	20

Table 6

## Online Community as Compared to Other Support and Information Resources

Item	Total Score <sup>1</sup>	Overall Rank
Physician	73	1
Nurse	58	2
MontanasGotGuts.org Website	57	3
Internet (professional websites and other online forums)	55	4
Others with IBD (who are not members of this community)	51	5
Professional journal articles	47	6
Family	46	7
Books and pamphlets	35	8
Friends	28	9

<sup>1</sup>Score is a weighted calculation. Items ranked first are valued higher than the following ranks; the score is the sum of all weighted rank counts.

### Community Participation Experiences

Participants were asked to rate fourteen statements pertaining to social support experiences and outcomes as a result of joining and participating in the online community. While all fourteen related to social support in general, six statements pertained more specifically to illness knowledge and information.

Regarding social support, table 7 shows that four statements in particular garnered the most positive response. Seven of ten participants indicated that they felt less lonely and have a more positive attitude towards themselves as a result of participation in the community. Half (five of ten) indicated that they felt more in charge of the course of their illness. Half also reported that they had made new social contacts. Conversely, half of the respondents reported that they did not make new social contacts, and did not feel more in charge of their illness. Furthermore, seven of ten did not feel more content with their

lives as a result of participating in the community, and most (nine of ten) did not feel more comfortable telling others that they could not do something because of their illness.

Table 7

Participant Responses to Questions Regarding Social Support (in descending order of highest agreement)

Statement	Strongly agree (%)	Agree (%)	Neither (%)	Disagree (%)	Strongly disagree (%)
I have a more positive attitude towards myself.	0	70	30	0	0
I feel less lonely.	0	70	30	0	0
I have made new social contacts.	10	40	20	30	0
I feel more in charge of the course of my illness.	0	50	40	10	10
I have more faith in my future.	0	40	60	0	0
It is easier for me to ask others for help.	0	40	40	20	0
I am generally more content with my life.	0	30	70	0	0
It is easier for me to tell others when I am not able to do something.	0	10	60	30	0

With respect to illness knowledge and information, four statements in particular elicited notable positive responses (table 8). As a result of participation in the community, eight of ten indicated that they felt they had more access to knowledge about their illness. Six of ten indicated that they understood their illness better, knew more about where to go with questions about their illness, and felt able to make better decisions with regard to their illness. On the other hand, participating in the community did not seem to have an effect on some knowledge-related behaviors. Eight of ten felt that they

were not better able to judge when they needed the help of their physician, while six of ten did not think participating in the community helped them to better understand information from their physician.

Table 8

Participant Responses to Questions Regarding Illness Knowledge and Information Support (in descending order of highest agreement)

Statement	Strongly agree (%)	Agree (%)	Neither (%)	Disagree (%)	Strongly disagree (%)
I feel I have more access to knowledge about my illness.	10	70	10	0	10
I know more about where to go with questions about my illness.	0	60	30	10	0
I feel more able to make better decisions with regard to my illness.	0	60	20	20	0
I understand my illness better.	0	60	20	10	10
I can better understand the information provided to me by my physician.	0	30	50	10	10
I am better able to judge when I really need the help of my physician.	0	20	50	30	0

### Summary of Quantitative Findings

The study population was a fairly well educated group, with most having been diagnosed with IBD for many years. A majority of participants reported positive gains in social support as they expressed feeling less lonely, and had made new social contacts as a result of joining the community. Low participation in the community was illustrated by

both participants responses and website analytic data. A majority of participants did demonstrate the importance of information about their disease as news articles and information sections were highly ranked in the areas of helpfulness and usefulness. The website as a whole ranked highly as a source for disease-related information. And, participants reported increased levels of knowledge and better understanding of their disease.

### Qualitative Data

Each interview transcript was analyzed and organized into significant data segments. Each of these segments was then coded with a word or short phrase that suggested how it informed or contributed to the research questions, and the purpose of the study. A total of 354 significant statements were identified describing how the participants experienced the online community. These statements were then arranged into clusters of meaning, removing any overlapping or repetitive statements. Four main themes emerged with 14 subthemes within these themes: Participants expressed a need to meet others with IBD, participants reported low active participation levels, participants valued the community as a source of IBD-related information, and participants valued the community as a source of social support. Qualitative findings, using verbatim responses from the participants, are presented within each theme. A short summary of relevant quantitative data that supports and collaborates the qualitative data will append each category.

### Theme 1: Participants Expressed a Need to Meet Others with IBD

When asked why they joined the community, nine of ten participants responded that their main impetus was to meet others with IBD. Three subthemes emerged in relation to this finding. Responses presented within this theme corroborate and further illustrate the quantitative data presented earlier in which a majority of participants reported to feel less lonely, and had made new social contacts as a result of joining the community. It should be noted that of the ten study participants, only three were considered acquaintances of each other at the time of the study, while seven did not know any of the other participant in the study. By the conclusion of the study, more than half had the opportunity to meet study participants, and others within the community, at recently held educational and public awareness events in Bozeman.

#### Subtheme 1: Participants Valued

Knowing that Others with IBD Live Nearby. Many participants felt comfort, and even reassurance, that other people who had IBD lived close to them. Melanie, a 33-year-old mother who lives in rural Montana, was happy to know that there were other people with IBD living nearby, saying, “I think the most helpful is just kind of knowing that, not that I didn't know there was other people, but like having real people sort of be on there that I can know.”

Julie is a 45-year-old mother with Crohn's disease who also has a young son with Crohn's disease. She sees the value in having peers accessible not only for herself, but more importantly, for her son. “Having somebody right here that's an hour and a half down the road is a big deal.”



Kyle, a 43-year-old man from Bozeman with Crohn's disease stated, "it is kind of nice and I was surprised to see there were that many people here."

Jason is a 24-year-old man from Billings, and is eager to meet others who live near him in Billings, but so far he's has been disappointed.

I am interested to know where people are and names and stuff. I think the map thing is cool. I noticed when I clicked on Billings – not that Billings is a small town or anything – I think I saw my name and one other person in Billings. And seeing that there's only one other person in Billings, I guess I could contact them.

Sandy, a 32-year-old woman from Bozeman, was pleased, but not surprised, to find so many others in the community. "I have seen others in the community on there – 40!"

Cindy, a 45-year-old woman from outside Bozeman, explained how just knowing people are nearby has impacted her.

I work from home. I work remotely. My whole team is in Virginia. They all work together. I never met any of them but they have all met each other. My boss is in Virginia and for me I always feel like the outcast and so just relating that back to this, knowing that there is people right here. I think that's going to help.

#### Subtheme 2: Participants Valued Finding Others

Who Share Similar Demographics and Experiences. Kyle expressed his desire to find others with similar disease issues who could share information to help him deal with his IBD. "I wanted to find what other people were doing or finding out what other people like if there was other little tricks or anything like that and just to find people with similar problems."

Beth, a 38-year-old mother from rural Montana and native of England, wants to find someone who shares some of the same circumstances she has.

I think it'd be nice to find somebody who is my age group and same problems, and how they deal with that. There might be someone on there that is in the same position that has a couple of young kids. I think it will meet my expectations once it gets more members.

She also finds the member profiles to be particularly helpful. "The profile is pretty good – the profile of each person, just to get an idea of how long they've had it and stuff like that."

Cathy, a 65-year-old woman in rural Western Montana, has a somewhat rare complication of Crohn's disease. Her physician told her of someone else in Western Montana with the same issue but, because of patient confidentiality, could not tell her who it was. She hoped to find that person online in the community. So far, she's had no luck.

I thought, gosh, I would love to talk to that person! I was hoping they'd show up on there and maybe I would figure out who that was. It would just be good to talk to someone who had the kind of carbon copy of my problem.

More specifically, participants valued the familiarity and shared Montana background and experiences with others in the community. Participants were asked during the interview whether they felt that a Montana-only online community was beneficial to them. Many participants found the Montana-only community a major selling point. Kyle appreciated the shared perspective that people from Montana may experience. "Just to find people with similar – it's hard to word that. We all kind of have the same understanding, I guess."

Kyle also saw how a Montana-only community could benefit him. He explained how there are many things unique to living in Montana to which people from other states may not relate.

Because I'm selfish, I like the idea of Montana because then you can have people that relate to, if for as silly as it sounds, if you're going snowshoeing, you're not going to that in Florida, like that kind of thing. So like if somebody says, "If I do this then I can pack, even just little things." Like I've learned a little trick about packing a rice ball when I go on hike. So I never had considered doing that, somebody told me about it and it works great with me with my Crohn's and what not. So that's something I don't think I would have about in Florida. So like so there's things like that that, so from a selfish standpoint.

Melanie appreciated the ease and comfort of a Montana-only community. "I think it makes it more personal again, and maybe, I mean, it talks about things specific to – I mean, there's not like specific Montana things, but it feels a little bit more homey or familiar."

Melanie also saw the formation of a local Montana network as cause for pride, as she stated, "I do think that Montana only kind of speaks to 'hey, this is important us in our state,' and we kind of form a sort of bonding in that way."

Sandy also sees the lack of other options for support and education in Montana as a reason why a Montana-only community can be successful.

I think the fact that it is only Montana makes it different from anything else that you can get online. If the idea is that it's only going be online, then I think it can be opened up. But then you're just becoming one of the other 50 million sites that are out there. The fact that it is only Montana and the fact that somebody who wants that doesn't have options, otherwise. I think it leads to a lot of pros to make it only Montana. I think there's a lot of – the CCFA has done a lot in the bigger communities and the bigger states. I think the fact that we don't have any kind of support group that they even sponsor in Montana at all. Because frankly, there's just so much out there – so many support groups, so much information, so much everything – that the people in the other 49 states really have a place to go.

Julie expressed how important building a local network is, for individuals and for the IBD community as a whole. "Having a network of people to support you is absolutely

critical and I'm fortunate to have a good network, but it's great to think about the idea of having more of a network locally.”

Subtheme 3: Participants Value the Opportunity to Meet Others in Person. One of the added benefits to a Montana-only online community is the potential it brings to meet others from on the virtual community in person, face-to-face. All participants expressed a desire to meet others offline, whether in a social context or in more intimate situations.

Susan is a 31-year-old woman with Crohn’s disease who is relatively new to Montana and has made few social connections thus far.

When I see something that is Montana-specific, it increased my hopes of getting to know more local people versus using the other online communities like Live Journal. Here’s this person in Georgia, or here’s this person in Texas. I’m looking for local support from people that I could go out to lunch with or watch a TV show with. To me, I like that it specific for that reason. There are plenty other avenues where if I want somebody that’s not local I could go there.

Susan went on to say:

It might be a good idea as an icebreaker, maybe have some kind of event or get together or luncheon. Get a luncheon or something for all of us to get to meet each other. The chance to get to see each other face-to-face is a nicer way to network and get to know each other.

Susan sees the website as a multifaceted tool to provide support on multiple levels, when she says, “This is for online support, local support, and face-to-face support.”

Beth has seen people she already knew in person on the website, and sees how that can help to facilitate communication online. “If you know someone, you’re more likely to share stuff with them on website, too, aren’t you?”

Susan, too, has connected with some people she already knew before joining the online community. “I’ve learned more about several people I already knew through the website.”

Julie has already seen dividends from her membership in the community.

I just did a big event and because of website there were some people that showed up that I wasn't connected to and that's huge. I mean, that's more important than the money raised at the event to me truly in my heart is the connections that are raised. So it has made a difference.

## Theme 2: Participants Reported Low Active Participation Levels

Qualitative and quantitative data, as well as website statistics, reveal a low level of active participation in the online community. This has not gone unnoticed to the participants in this study. The participants did, however, offer explanations and theories as to why interaction was so limited, and posed suggestions to garner greater participation in the future. Quantitative data presented earlier further illustrates the low participation levels described in this theme. Both website analytics and self-reported website usage data corroborate participant statement presented within these subthemes.

### Subtheme 1: Participants Would Actively Participate More if There Were More Contributions by Others. To begin,

everyone who offered this explanation realized that it was quite a conundrum, and a contradiction on his or her part. In short, they were saying, “If someone else does it, I’ll do it!”

Jason summed up the predicament very well.

It's kind of hard to get the ball rolling when nobody is really jumping in there. I guess if I were seeing more people on there and more activity, then I suppose I might jump in. But I understand that I've got to do that. I'm sure people think the same thing.

Susan offered her assessment of the situation.

The only thing that I was really kind of let down with was lack of people participating. I've been in student organizations where it's like a double-edged knife. I've been in an organization where you don't have many numbers. The thing is we need more people to join to have more members. It's like a vicious cycle. Sometimes I'll look more because I see there is more activity. If people start seeing more activity, hopefully they will start coming on board. It's a double-edged sword.

Cathy is more than willing to participate more – if more people would ask questions. “If there are more people joining with questions or problems, I would just get right in there and answer. I guess I'm not seeing too much of that.”

#### Subtheme 2: Participants Suggested

Personality Traits as a Barrier to Participation. Many stated that shyness, or their own personality type, was a hindrance to actively participating in the online community.

Cathy described how her personality prevents her from participating.

I'll just say my personality type. I shy away from participation things in a way. Some people are more that way. I would be the shy person peeking in but not making too much noise. I just think my personality type.

Jason also confessed to, “being a little shy right off the bat” as a reason that he's been reluctant to post on the website. He went on to explain that he was also “a little bit hesitant to put in too much information.”

Kyle also felt that he might not be “brave enough to say something.”

Melanie explains how her personality has inhibited her participation.

I guess something that's within me. I'm not a big blogger person. I know on one of your things it was talking about wanting people to be more involved, which would help the website a lot, but I'm also like, 'Oh man, that's just not me,' to really put myself out there or post things. I don't really do that anywhere else and maybe as I become more familiar with it I will. So I think it's just -- that's more my thing I guess.

Beth realized that people may be hesitant initially, but given time, and more participation by others, things will pick up.

I think that people are hesitant to come forward at this point, but I think the more people that come on and talk about their stories, I think you might find there are going to be people that kind of talk to each other. They click, like, "You sound like you have the same as me."

### Subtheme 3: Participants Suggested

Time as a Barrier to Active Participation. Another popular reason for non-

participation is lack of time. More than half of the participants state that they just needed to make visiting the website a greater priority.

Sandy expressed the sentiments of many who work with computers all day.

I spend so much time on the computer at work, you know, my everyday life. I just try not to get on the computer when I get home. That's kind of the main thing. I like to be around real people.

Susan explained how her life adjusting to a new city leaves little time for participation in the website.

Whenever you are in a new area, you start a new job. You have to get in routine – not necessarily routine, but you just have to adjust to the change. I hate going to work, and the minute I get home all I want to do is go to sleep. Then I wake up the next morning, and I really don't have enough energy – even though I am on the vitamin D and B12. Just emotionally, the new experiences drain you. You are just trying to get used to the new schedule in your life.

Beth also expressed a lack of time. “For me personally right now, it’s time. Every time I sit down at the computer, my time essentially is me time. But, I just don’t have a lot of time to get on it.”

Melanie, too, blames her inactivity on a lack of time and adds, “if I had more time I might do more with the website.”

Julie also acknowledges a lack of time, but also sees how she needs to make a commitment to participate more.

It's just really time. There's just so much. I work full-time. I have a son who's got the Crohn's and has not done great. And I've got a daughter in college, it's just time. I've been fund-raising and doing other things so it's just a matter of making that commitment to just go do it. But I think it's just committing to it. It's like not making it a passive thing like, “Oh, I should go check the site when I have a minute.” It should be, “Tuesday mornings I check the site!”

Julie also feels a responsibility to help others, and uses that as a motivation to find the time to participate.

I'm committed as well to doing a better job on my end of being there for those people who don't have a network yet. Like I feel like I'm okay, but I need to give back to other people who are kind of starting out where I was a few years ago.

### Theme 3: Participants Valued the Community as a Source of IBD-Related Information

While most participants stated that their primary reason for joining the community was to meet other people with IBD, they placed greatest value on the gaining knowledge and information about IBD as a result of participation in the community. Nine of ten participants stated during the interview that the website had a positive impact on their level of IBD knowledge. Four themes emerged relative to information and knowledge. Quantitative data presented earlier further illustrate the affect on participants’



illness knowledge as discussed in this theme. The news and research section was rated as the most useful to participants (table 5). Participants ranked the website as the third most helpful source for information (table 6). And, a majority of participants reported that as a result of joining the community, their access to information about IBD had increased and they felt they understood their illness better (table 8).

Subtheme 1: Participants Suggested that Information Most Helpful Aspect of the Community. Not only did nine of ten

participants report that the information available through the website was most helpful and useful to them, they also contend that information seeking was a major reason for joining the community.

Melanie sees the featured articles as well as the experiences of others as valuable information. “I like having connections to articles. I appreciate that. And then I guess, like, people's personal experiences that they talk about is also, on a very individual case-by-case basis, it's still information.”

Sandy feels that information is vital.

Sharing information is key. “I heard about this new drug. Has anybody else heard about it?” And having a conversation on a fact or an article. The articles and the information portion of it -- articles, study updates, those kinds of things are interesting to me. And, yes, if there were more actual information, it would give me a reason to go.

Cindy appreciated the steady supply of news and articles, too. “For me it’s been the little news briefs that you have been posting and I think that it’s you that is posting them, those have been the most helpful for me that is what I get the most out of.”

Jason was happy to find out about CCFA, and visited their website to find much more information.

I did find that link to CCFA on the website. So I went to that. I went on their website and was reading on there. And that was really cool. I saw that they were doing some clinical trials and stuff. I thought that was really cool just to see what's going on.

Susan found the Google news feed very helpful. "You have that nice little Google alert built in. I think I will have to look at it more. That's really cool. I may have seen one or two articles pasted on the site that were pretty helpful."

She went on to tell how she appreciates having access to a gastroenterologist via the website.

I really like the fact that you have a real G.I. that is willing to be a part of it and be helpful. For instance, like I've said in my past, I've been unemployed and I haven't had health insurance. What can I do? I can't afford to go see a doctor. It's nice that you are given the actual opportunity for somebody of the profession to actually be there. It's not just for a monetary reason.

Kyle sees how the information provided may not help him now, but is there for a resource in the future.

I'm fortunate because I don't have some of the symptoms as bad as other people do. I do feel fortunate, believe it or not. But I do see where people can use it and just knowing about the different medications and like updates and options.

Julie understands how important it is to keep the information new and current, whether it is generated by members or posted via the site administrator.

Focus on making sure that there's something new on there. New articles and new research and things. That's the critical part, I think, to revisiting any web based application. There has to be new content, really anytime you go there.

Jason relayed an experience in which he found via the website helped to reinforce something he was discussing with his physician. He expressed a sense of satisfaction and competence knowing he was well informed.

I guess one big one with me was ... I was looking at a few articles when I was on there a few weeks ago. I just started reading some articles and seeing the bacteria thing is coming along. And I remember a few years ago when I first started talking to my doctor about my diet, Dr. Landsvert said, 'I'm not going to tell you it doesn't work. But there just aren't studies supporting it.' And that was four or five years ago. And then I saw Dr. Landsvert a few weeks ago. I asked him about it again. And he said, 'Yeah, it's really growing! And people are seeing some results ...' and stuff. And, now being online and seeing that there's more of this probiotic stuff, yeah, that was encouraging.

Even the well-informed participants felt a need to gain more information about IBD. A majority of participants claimed to be relatively knowledgeable about IBD, most after many years living with the disease. Many had a profound interest in staying well informed and a desire to learn stay up-to-date on IBD news and research, even if their disease was in a quiescent state.

Cindy has been relatively symptom-free for a few years but still wants to be informed of the latest news and breakthroughs.

Well, for me, I've been lucky. I haven't been sick for about three years so I've kind of had to quit paying attention. I still listen to the CCFA webcasts when they come out, but I haven't been doing a lot of research on my own. I haven't had a need to. This site has made that easier to do.

With Crohn's disease affecting both her son and her, Julie is especially driven to gain as much information about IBD as she can, and appreciates the information others contribute to the website.

I think that because of my personality from the beginning I was researching and finding out everything I can. Because there's other people on the site finding new research stuff, and I try to stay on top of it, that's a benefit for sure. For me,

knowledge is power so I try to find the latest, greatest on my own regardless. But sharing it and also knowing that other people are looking is nice.

Sandy is also very knowledgeable about IBD, as a 15-year veteran of the disease, and with a father and sister who also have IBD. But even she could find items of value on the website. She was asked whether participation in the community had affected her knowledge level of IBD, she replied, lightheartedly, “probably not a lot – just because I try to keep up on the newest stuff. I have learned different things. Like Eisenhower had Crohn’s disease. Random things!”

Cathy feels she hasn’t learned anything new that will help her, specifically.

Well I’m going to say that there hasn’t been anything yet. Not that I don’t think there can be. I just haven’t come across anything yet. I’ll just say 41 years learning, dealing with it and going through it, I may just be way ahead.

Subtheme 2: Participants Suggested that Information More Valuable When it Comes from Others with IBD. While participants

expressed their desire for more information about IBD, they placed greater value on information that is shared from the experiences of others with IBD. Beth appreciates getting advice on everyday issues pertaining to IBD.

One thing works for one person, and one thing doesn't work for the other person. Some people can eat this and some people can't. I don't think there's one sort of recipe. Some people might want to submit things that they make when they're having a flare up, things that are generally easy on the tummy just generically everywhere. I'd like something like that. Just reading a lot of people's stories, you can learn a lot from other people's experiences, too. Just what they're doing drug-wise, and what they do for certain situations.

Jason is eager to gain information from others in the community. “I’d be happy to just say, ‘what are you doing? The triggers -- and here’s what I’m doing. Have you found

anything that's more effective or less effective?' Yeah, I'd be happy to do something like that."

Kyle sees the value in getting information from other people who have IBD in addition to that which come from professionals.

I do feel like I can throw up something on a blog and somebody will say, "I've tried that," or, "have you tried this? So I think that maybe I feel like I have a little place where there might be some guidance for real life, not a book, not from a doctor, not from somebody – the real-life thing, I think, is big for me. I want to find what other people were doing or find out what other people, like, if there are other little tricks or anything.

Melanie sums up her feelings on sharing information.

I think just having another resource, I guess, that's more from the people as opposed to here's what I'm getting from the doctor or from the drug company or whatever. Just someone else who is coming from like a layperson perspective, I think. You know, people's personal experiences that they talk about are also, on a very individual case-by-case basis, still information.

Subtheme 3: Participants Expressed a Need to Share Information and Experiences with Others. Not only do participants want to

get information about IBD from others with IBD, they want to share their experiences and advice with others who may be in need.

Cathy was very adamant about her desire to help others.

It could be me, you know, helping someone who is new that is exactly like me. I could offer help to them and that feels real good. I can help somebody else with questions. Somebody needing help in something I had trouble with and found a way to help to make it work. I love sharing any of that if someone asks.

Sandy gets right to the point. "The biggest thing is I want to share information. I want to help people!"

Beth is similarly eager to share her experiences with others, warts and all. “I think it should be one of those ones where it doesn't matter – embarrassing things and all. I think that just makes it real interesting. I think, ‘the more embarrassing, bring it on.’ Someone will appreciate it.”

She also very simply stated what was the underlying sentiment of most participants. “Everyone likes to think that they can help other people!”

Subtheme 4: Participants Exhibited a High Level of Lurking Behavior. As illustrated in both quantitative and qualitative data, active participation in the online community, such as posting comments and direct communication with other members, is low. However, as seen in previous themes, participants do report that they regularly visit the website to read the current articles and posts.

Cathy describes this phenomenon quite well.

Yeah, some just lead and take over and others will read quietly and zip in and out. I am in there reading. I go in there and I am reading everything. Now I'm not writing, but I don't really read any questions that need answering, so I don't know how to participate more.

She also explains how she keeps checking back, hoping to find someone who is “just like her.”

If I could share something of myself or just reading their posts, I guess, trying to find someone that's about where I am and then we could talk, I guess. I haven't really done too much of that. But I keep checking in.

#### Theme 4: Participants Valued the Community as a Source of Social Support

Eight of ten study participants reported that the community provided some degree of social support. Four subthemes emerged from the qualitative data demonstrating the affects that participation had on support experiences and perceptions. Quantitative data presented in table 7 corroborates some statements presented in subthemes related to social support. As noted earlier, a majority of participants indicated they felt less lonely and had made new social contacts as a result of joining the community.

##### Subtheme 1: The Concept of “Support”

Meant Something Different to Many Participants. Beth sees “support” as someone

who can understand what she’s going through and can relate to the day-to-day issues.

Maybe if I’m having a rough day, I can sit down on a computer and be like “It really sucks today. I had to run to the bathroom, and missed my daughter coming out of school.” I can get help on that situation where on a particular day, you had a bad experience, and you just had to tell someone that understood. My husband tries very hard to understand, but he doesn’t understand. It doesn’t matter how hard he tries -- he doesn’t understand my predicament. If I say, ‘I need to go to the bathroom,’ he says ‘There’s a bathroom up the road.’ No, I need to go now. I don’t care about the gas station five miles up the road. I need to go right now. It’s really hard that they don’t understand the urgency of that situation.

She also feels that “support” is a two-way relationship and because she has not actively participated in the community, she has not, and does not deserve “support.”

Yeah. I didn’t really put myself out there yet, so I don’t receive any support. Like I say, I didn’t really feel like I deserved any at this point, but it was interesting listening and reading about other people. I didn’t get much from it yet, but you never know. There might be someone on there that is in the same position that has a couple of young kids.

Cathy also sees “support” as actual conversations with other people who can share experiences directly.

Well, I don't know that I've gotten support yet but I keep hoping. Talking and sharing, more questions and answers, to me, is the biggest thing I'm hoping for on this site. I just don't think that I've found that yet.

Sandy feels that "support" is strictly an emotional experience. Information? "It's a kind of support. But I don't consider it support." She continued:

Support is, 'I'm feeling really crappy today, oh, I hope you feel better.' Sharing information is, 'hey, I heard about this new drug. Has anybody else heard about it?' Having a conversation on a fact or an article. It's the feelings part. It gets into a slippery slope. And it gets into the poor-me-game. And I just don't -- it's hard enough for me to stay positive without getting around people who want to be negative about it.

She also adds that she doesn't expect an online community to provide support, as she defines it. "I live with two other members of my family with Crohn's disease and one who's dealt with Crohn's disease for 20-some years. I have enough support in my everyday life that I don't really seek it from online sources."

Julie explains how "support" is a vital component to her disease management, in an emotional sense. But like Sandy, she doesn't look to the online community as a source of emotional support.

I do have people that are there and that will answer a question or give me their thoughts or tell me their experiences immediately. But I think that's the exception, not the rule. I really, really, really believe that it's part of staying as well as you can be -- not necessarily in a physical sense because you can't always control that but in a mental, emotional sense.

Jason, on the other hand, sees "support" as gaining information and knowing that there are others experiencing the same things that he.

Yeah, it's good to know if I'm having problems or having questions. For instance, I've been having these problems or I'm thinking about getting on this drug. Do you guys recommend doctors or something like that? I think that's been good and seeing that there are people on there that are in your position is good, too.



Melanie also sees sharing information as a form of “support” and feels she has gained a level of support despite not making any personal connections via the website.

It’s definitely increased as far as just having other people that you know locally who have it and who are interested in sharing their information. Yeah, so I think it’s definitely increased whether I like have specific contacts that I personally have a conversation with.

Subtheme 2: The Term “Support” Sometimes Garnered Negative Connotations from Participants. As stated earlier, some

participants see “support” as strictly an emotional relationship between two people. That said, they see “support” as spending time dwelling on the negative aspects of the disease, complaining and pitying, is not a constructive use of time.

Sandy touched on this earlier, and had more to say on the subject. “I don’t want to sit there and talk about Crohn’s disease for two hours. It’s not my life. I just feel like when people get in a group, they cannot help but be competitive against it.”

She goes on to say:

I don’t want to be your cheerleader. I have cheerleaders. I am a cheerleader to others. But I can’t be a cheerleader to some faceless person. It’s not who I am. It’ll never be who I am. Frankly, I don’t want to hear about the fact that, you know, you have a little bit of pain. So you’re going go apply for disability.

Finally, Sandy adds:

I don’t mind hearing about experiences with different medications and stuff. And I don’t mind answering questions on experiences that I’ve had with it. It’s a very slippery slope when people get into the poor-me-game.

Similarly, Beth is reluctant to share too much for fear of soliciting unwarranted and unflattering sympathy.

I didn’t want to go on there and be like, “oh, I’ve got Crohn’s so bad” because right now I’m at an okay spot. I didn’t want to go on there and be like “oh, it’s so

horrible having Crohn's" because it sucks, but it's not cancer. I didn't want to be the one on there that is "poor me," and then someone comes along that's had 10 million surgeries and it's like "what are you complaining about? It's not that bad."

But, Beth thinks it's just human nature and that there will always be some people who are complainers. "I think it depends on the person. There are cup half full and cup half empty. I think you're going to get that with anything, not just Crohn's."

Subtheme 3: Participants Demonstrated that the Potential for Support can be as or More Beneficial than Actual, Active Support. Even though active participation in the online community was low, almost all participants report receiving some sort of social support, however they define it. How can that be?

Many suggested that the act of joining the online community, and realizing that there are many other people who also have IBD living nearby had a positive affect on their mental psyche.

Jason finds solace in knowing there is help nearby if he should need it. "It's good to know if I'm having problems or having questions, that there's someone out there. I think that's been good seeing that there are people on there that are in your position."

Melanie indicated that she has felt an increased level of support as a member of the community, even though she has had made minimal contributions. "I think it's definitely increased whether I have specific contacts that I personally have a conversation with. It would be my choice to do that, which is empowering. But yeah, just knowing there are people out there."

Kyle expressed a similar sentiment.

I think it's been more of a mental thing for me. I think just because of knowing that there are people out there doing the same thing. I don't know if it makes me feel more settled, maybe? I think it's good for my mental being, anyway.

Cindy sums it up well. "But now I'm thinking, it's just the idea of having a network. You feel not alone and that there help if you want it -- like the potential for it. Does that make sense?"

Subtheme 4: Participants Valued Feedback within the Community, Whether Active or Passive. Feedback can be a beneficial outcome of community participation. And, while there has been little active feedback transpiring within the community, many see how valuable passive feedback can be. Many simply read the experiences of others and, as a result of social comparison, can gain positive feedback.

Beth sees how sharing her personal experiences can have a positive impact on others.

It'd be fun to share people's stories and really honest things about day-to-day life. I think you have to get down to the nitty gritty and say 'This day was horrible because this happened.' I think it makes people feel that there are other people like that in the same situation, basically. Just to feel that there are other people out there with the same problem. It just makes you feel like less of a weirdo.

She goes on to add:

At the same time, you also have to put yours into perspective. For everybody out there, there's somebody that's got it worse. It does put it into perspective. I go "Okay, I'm not that bad yet. I can still do this and that. I'm going to go and do it."

Kyle appreciates active feedback he's received from the community. "When people give feedback, you just kind of realize that, like, you're not the only one."

But, passive feedback has been more readily available just by reading the experiences of others on the website. Kyle sees that as beneficial, too.

I don't do certain things before go to a gathering or will avoid certain circumstances and then you start to kind of wonder, 'is it me is it in my head?' But then you're like, 'No, okay, I saw other people were doing the same exact thing.' So I think that's good for my mental being anyway.

Susan expresses a similar feeling when she sees that others reinforce some of the knowledge she has regarding IBD. "Sometimes it's a relief to go to something like MontanasGotGuts or some other online forum to see people that know that Crohn's is not because of the change in our diet."

### Outliers of Significance

Data from both the quantitative and qualitative findings presented an interesting juxtaposition of two participants, Sandy and Susan. Both are thirty-something-year-olds living in Bozeman. Both have Crohn's disease. Both had jobs and were married or lived with their significant other. But the similarities ended there.

Sandy has had severe Crohn's disease since her teens, and has endured many significant complications over the past few years. She also has great financial issues as a result of her disease. She does have a good job, with great health benefits, and a very understanding and accommodating work atmosphere. Sandy was the only participant to rate her health as "poor." However, her responses and attitudes exhibited during the interview process were among the most hopeful, accepting, and optimistic of the entire group. She expressed, on multiple occasions, that she didn't want to whine about her disease, and didn't want to be around people who did. She prides herself on being very

well educated about her disease, and her knowledge was evident. She appreciates the online community as a resource for information, but doesn't want her disease to become her life.

Susan has moderate Crohn's disease, has not had surgery, or any of the more significant complications that can arise from the disease. She also is in great financial difficulty due to her medical bills. Adding to these difficulties is that she has not been able to find, or keep, a job. She recently was fired from her job because, in her words, she "missed too much time and was sick all the time." Susan rated her current health status as "fair." But, in complete opposite to Sandy, Susan's responses and attitude throughout the entire interview process was one of negativity, complaining, and a very overwhelming "poor me" mindset. In contrast to Sandy, Susan desperately wanted someone to talk to, someone to tell her troubles to, and someone to help her. Susan also considered herself to be knowledgeable of her disease, but this was not evident during the interview.

These two scenarios illustrate the two extreme, outlying experiences of the study sample. Both instances illustrate the effects and influences that illness knowledge, perceived social support, illness representations, individual environment, experiences, and perceptions, social networks, and successful coping strategies can have on the HRQOL of someone with a chronic illness, independent of actual health status or disease factors. And, they demonstrate the difficulty in providing beneficial and successful support and information opportunities to all segments of a community.

### Chapter Summary

Chapter 4 presented the responses from the surveys and one-on-one interviews of the 10 study participants. Data concerning participant demographics, Internet usage, and website analytics and usefulness were presented along with data regarding community participation experiences. Sixteen themes concerning a need to meet others with IBD, low active participation levels, the community as a source of information, and the community as a source of social support emerged from the interviews.

Chapter 5 will present an overview of this study and the answers to the research questions. A discussion of the findings, its implications, and recommendations for further research will also be presented.

## CHAPTER 5

## CONCLUSIONS

Introduction

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge. Research shows that access to social support can help mitigate the negative psychological effects of chronic illness, and positively influence health outcomes, ultimately improving the health-related quality of life of those affected (Colineau & Paris, 2010; Moskowitz et al., 2000; Shigaki et al., 2008).

This chapter will present an overview of study, answer the research questions posed, and discuss how the results of this study compare to the current literature. Recommendations for future practice and suggestions for further research are also presented.

Overview of the Study

Many with IBD in Montana lack access to the social support needed to manage their disease successfully. If a viable, accessible, and beneficial opportunity were available, it would be crucial to have the endorsement of local physicians. The problem

addressed in this study was that those serving individuals in Montana with IBD need to know how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge.

Participants were recruited from the membership of the online community, MontanasGotGuts.org. A self-report survey instrument was initially used to obtain demographic data, and data on how participants report experiences within the online community. Next, qualitative research methods, using semi-structured interviews, were conducted to collect more insightful, narrative data not possible through other research methods. Qualitative methods allow the researcher to expand on descriptive data collected, and find out why participants responded the way they did.

### Research Questions Answered

#### Research Question 1

How do participants assess and describe their experiences within the online community? The findings in this study illustrate both the positive and negative aspects of support communities, in general. First, the participants in this study expressed and demonstrated a desire to meet others with IBD. More specifically, they greatly desired to meet others with IBD who share a background similar to their own. These similarities are displayed in demographics such as age, gender, and household situation, but most notably



geographically in that they value meeting other people in Montana. Many participants felt that living in Montana was a unique experience, and one to which people outside of Montana could not relate. Second, they also felt comfort in knowing that there were other people with IBD who live nearby, whether in the same neighborhood or in the same region of the state. Further, this geographical nearness allowed participants to entertain the possibility of meeting others with IBD face-to-face, which is something that is not generally possible or probably through other online communities that are open to worldwide membership.

Unfortunately, participants in this community experienced many of the same negative roadblocks and experiences commonly found in other online and face-to-face support communities. Most notably, many participants commented on the low activity levels on the website as demonstrated in low interaction among members, little sharing of experiences, and few questions posed. However, participants also recognized the resulting conundrum, as most members stated that they would participate more if others would participate more. Many concluded that they felt that the community was on the verge of turning a corner and participation would increase; it would only take few people to actively participate more and on a regular basis. But, most participants were reluctant to be that person to open the door. Many identified lack of time as the culprit in their lack of participation, while others felt it was just their own personality that hindered their full participation.

Overall, most participants reported that the community met their initial expectations. Primary reasons for joining for many were to meet others in Montana with

IBD and to gain more information about IBD. Participants felt comfort to learn that there were many other people in Montana with IBD, and found the news articles and research information about IBD very beneficial.

### Research Question 2

How have their experiences impacted their HRQOL as exhibited through impacts on social support?

Social support interactions via the online community were demonstrated in a variety of ways. Participants displayed differing understandings of what social support means. Many equated social support as only emotional support and did not relate gaining information from others as a form of social support. And, while there was much information support exchanged, albeit generally in a one-way direction, little emotional, appraisal, or tangible support was exchanged or even offered through member interactions. Participants did, however, passively gain feedback by comparing their experiences to experiences and stories of others, and by comparing their own knowledge to information obtained in articles and from the experiences of others. This shows that the concepts of social comparison and normalcy were demonstrated within the community.

Also notable were the negative connotations members had with just the idea of emotional support. Many expressed a reluctance to engage in dialog with others in the community for fear of being barraged with sad stories and poor-me attitudes. And, still others were reluctant to share their personal feelings and emotions for fear of being seen as a complainer and not worthy of sympathy and support.

Perhaps the most interesting finding in this study was that although little active support was offered or exchanged within the community, participants still reported positive gains in social support. Participants reported that they were less lonely, had a more positive attitude towards themselves, and had met new people. This leads one to believe that the potential for support, and the perception that support is available, whether acted upon or not, can be just as beneficial as active support. And, while social support is generally seen as four faceted, this study supports the ideas of a fifth facet, network support. As many participants stated, just belonging to the community and knowing that there are others with IBD nearby who share the same experiences was a comfort.

As research suggests, positive gains in social support, and in particular perceived social support, can result in increased HRQOL for those with chronic illnesses. In this study, participants did report positive gains in perceived social support as a result of participating in the online community. Therefore, participating in this online community may provide members the potential to see positive affects on their HRQOL.

### Research Question 3

How have their experiences impacted their HRQOL as exhibited through impacts on illness knowledge?

Study participants overwhelmingly reported that gaining information was the most useful and helpful aspect of community. Even those who have had IBD for many years and felt well informed had a desire to gain more information and found the information offered through the website very beneficial. Many participants also suggested that information was most valuable when it came from others with IBD.

Participants also had a great desire to share information and experiences with others, especially those who are newly diagnosed and need help. Even though there was little active participation in community, via posting and dialogue, many participants exhibited lurking behaviors and monitored site regularly to find new information, and to read articles and posts from the administrator.

Many of the study participants did report gains in their own knowledge of IBD. Research suggests, however, that the act of information seeking itself demonstrates a problem-based coping behavior that can positively contribute to HRQOL of those with chronic illnesses. The findings of this study show that participants placed great value on seeking and gaining new information about their disease, whether or not the information itself was valuable or useful at that stage of their disease. This leads this researcher to conclude that the HRQOL of some participants may be positively impacted as a result of gaining disease-related knowledge, and actively seeking out information about their disease within in the online community.

#### Comparison to the Literature

The results of this study support several of the findings in the literature and highlight areas where further research may be needed.

Previous research has shown that information support tends to be the most valued and exchanged commodity within support communities (Bunde et al., 2006; G. J. Johnson & Ambrose, 2006; McCormack & Coulson, 2009; O'Grady et al., 2008). The participants in this study overwhelmingly valued information support over the other

facets of support as news and research about IBD were the most highly rated aspects of the website. Subsequently, as also seen in the literature, participants in this study shied away from emotional support situations (Casati et al., 2000; S. A. Cudney et al., 2002; Curtis, 2005; Hall et al., 2005; Lonardi, 2007; C. F. van Uden-Kraan et al., 2008).

Lurking behaviors were also demonstrated and described by study participants in that many passively monitored the website and read everything that was posted. Research suggests that lurking behavior seen in online communities can be as beneficial as actively participating in dialog with other members (M. A. Lieberman & Goldstein, 2005; O'Grady, 2008b; C. van Uden-Kraan et al., 2008).

While participants in this study also expressed a great desire to gain information about IBD through membership in the community, they found most benefit in gaining information from the stories and experiences of others with IBD. This agrees with many adult and community learning theories impact (Bunde et al., 2006; Colineau & Paris, 2010; Dennis, 2003; Hall et al., 2005). Adult learning theory states that adults want information that is useful to them, will help to address their specific problems, and comes from their peers whom they perceive to have experienced similar situations (Heuer, 2007; Largent & Horinek, 2008; Merriam, 2008; O'Grady, 2008a). In addition, community learning theories illustrate how members of groups not only want to learn from others, but also find great satisfaction in sharing their experiences, known as information forwarding, with hopes that others can learn from their experiences (Ellis, Mullan, Worsley, & Pai, 2012; Fox, 2010; Kim & Lee, 2014; Miller, 2010). The participants in this study expressed a great desire to help others by sharing their own personal

experiences with IBD. Unfortunately, many were inhibited from doing so, while many were waiting to be asked for their help.

Participants' need and desire for information about their illness demonstrate the use of information seeking as a problem-focused coping behavior. Information seeking describes a person's need to access information sources in an attempt to alleviate uncertainty, and enhance decision-making skills concerning the problem at hand (Ellis et al., 2012; Groarke et al., 2004; Kim & Lee, 2014). Having access to information may also give a person a sense of reassurance and greater self-efficacy, and in the case of those with chronic illness, make them feel more in control of their disease. Lazarus' coping theory suggests that the successful coping activities, and in particular, problem-focused coping, are associated with successful illness adaptation and improved outcomes, which may, in turn, positively affect HRQOL (Kim & Lee, 2014).

The literature suggests that social support and learning is best experienced between peers who share similar backgrounds, whether demographic, geographic or experiential (Colineau & Paris, 2010; G. J. Johnson & Ambrose, 2006; Marienau & Reed, 2008; Sarasohn-Kahn, 2008; C. Taylor et al., 2007). The participants in this study reported a strong desire to share their experiences with others of similar backgrounds, and more specifically, with those who lived in Montana. Community members valued the concept of a Montana-only community where they could relate to the experiences of others that are unique to Montana.

The literature also suggests that while social support is beneficial to those with chronic illness and can positively influence HRQOL, it is perceived support that is shown

to be more beneficial support (Krause, 2003; Lakey, 2008; Uchino et al., 1999). The participants in this study demonstrated this concept very distinctly, as even though actual active participation in the online community was minimal, participants still reported positive impacts on social support. This leads one to conclude that just the perception of support, knowing that support is available, and nearby, can be extremely beneficial to those with IBD.

The social support research community has generally agreed that there are four facets to social support: informational, emotional, appraisal and tangible (C. Campbell, 2001; Dietrich, 2010; Olsen & Kraft, 2009; Uchino et al., 1999). One facet of social support that is not as prevalent in the literature is network support, which involves broadening one's social network and meeting new people who can potentially provide support, if needed (Cutrona & Russell, 1987; Hlebec, Mrzel, & Kogovšek, 2009; Laireiter & Baumann, 1992; P. K. H. Mo & Coulson, 2008; K. P. Smith & Christakis, 2008). The participants in this study demonstrated the value of network support very clearly. Many expressed that just knowing that there was a network of people in Montana with IBD that could be available to them was a tremendous benefit of joining the community.

#### Study Conceptual Model Revisited

As a result of the findings in this study, the original conceptual model presented in chapter one (see Figure 1) was revised. A social ecological framework is used in the revised model to illustrate how both individual and environmental factors, as also suggested in Wilson and Cleary's HRQOL model, can influence HRQOL (see Figure 2).

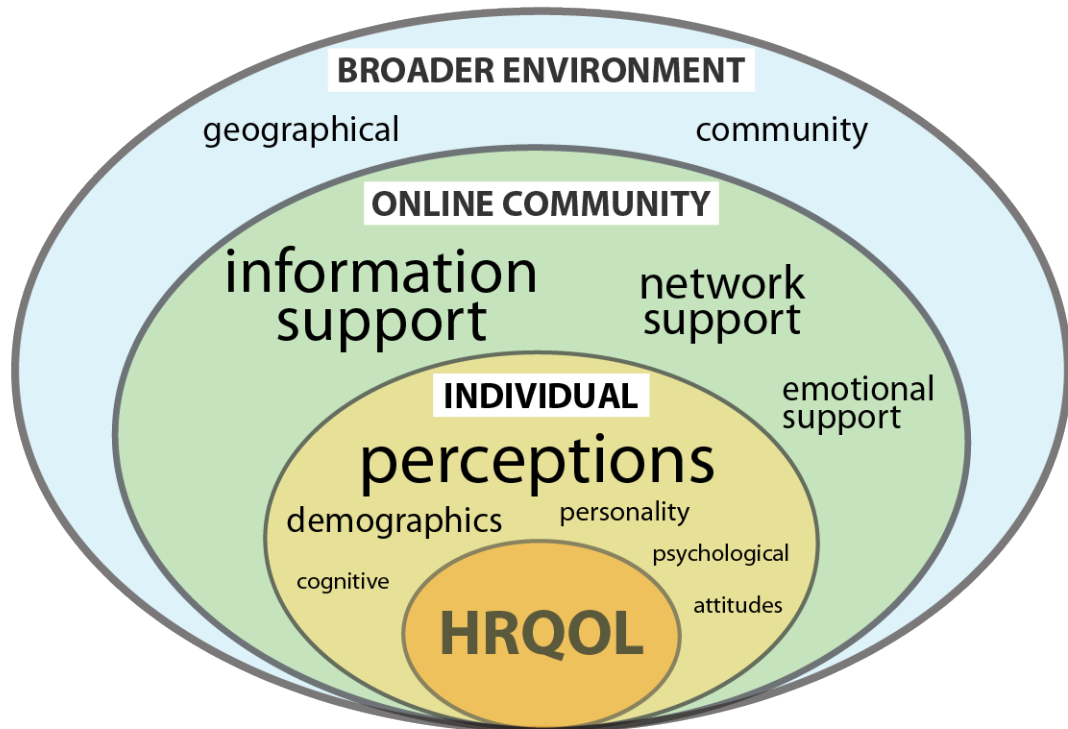


Figure 2. Revised conceptual model for the study

Three of the more significant findings of this study are reflected in the revised conceptual model. First, the study results demonstrated that information support was the most valued and sought facet of social support within the community. Therefore, the model presents “information support” as a much larger positive influence on HRQOL than “emotional support,” the latter of which was less valued and garnered negative connotations among many study participants. Second, the significance of perceived social support as an influence on HRQOL was also a major finding in the study. As a result, individual “perceptions” are presented as a relatively large influence on the individual. And, third, the importance of the size and scope of an individual’s social network as a contributor to perceived social support and access to illness knowledge led to the addition



of “network support” as a major facet of social support, and a major influence on HRQOL.

### Recommendations

A descriptive study allows the researcher to describe a phenomenon in its current state – the “what is.” One of the advantages of conducting a descriptive study is that the findings can fill the gap between the “what is” and the “what we want to happen,” and be used as a needs assessment in reaching preconceived goals and outcomes. The outcomes of this study allow this researcher to offer recommendations to a variety of potential readers and audiences – the researcher herself, the national IBD community, those with IBD, physicians and healthcare professionals who serve those with IBD, and administrators of online support opportunities to other chronic illness communities.

### The Researcher

As the researcher in this study, and the administrator of the online community, the following recommendations were made to improve participation in the online community, and meet the expectations of its members.

First, the Montana-only membership in the online community will be maintained. The majority of participants in the study appreciated that the community was restricted to Montana residents. This not only provided members others with whom they share unique experiences and backgrounds, but also seemed to foster a greater sense of community, and a feeling of pride among members. Suggestions were made that perhaps this website could be one component of a larger website in which other states would have similar

communities, thereby maintaining the intimate appeal of the Montana-only community but also providing access to a greater number of members, and perhaps, more interaction. While this was the ultimate goal of the developer and administrator of this website, it may also be a beneficial suggestion to other national websites, namely the CCFA website, to allow for segregation of members into state-only groups and perhaps replicate the intimacy of the online community in this study.

Second, more IBD-related information will be provided on the website in a more consistent manner. The participants in this study greatly appreciated and benefited from the variety of news, research articles, and other information provided on the website. While every attempt was made to keep the information fresh and current, there can always be improvement in this area. Because of the apparent lack of activity on the website, the administrator did not initially realize that members were visiting the website regularly to read any and all information posted. The lesson learned here was not to assume people are not reading what is posted. Information may be the most valuable commodity the online community has to offer.

Third, the online community will be promoted as an information network, not solely as a support network. The results of the study clearly indicated that participants had a negative attitude towards support groups. Not only did they express that they valued information more highly than other services available on the website, they also viewed emotional support in a negative light. Efforts will be made to refocus the mission of the website to highlight its information congregating and sharing aspects, and to dispel

preconceived connotations that the community is one for only sharing sad stories and garnering sympathy.

Similarly, promoting the online community as a network, a place where help is available if you need it, will also be a future focus. Efforts will be made to demonstrate to potential members the benefits of just belonging to a community – the opportunity to meet new people with the potential to meet others face-to-face. Expanding the social network of members, meeting new people, and the potential to meet others face-to-face are aspects of the community that study participants found beneficial, and will be used to recruit more members.

#### National IBD Community

The goals of the Crohn's and Colitis Foundation of America (CCFA) are to serve those with IBD by providing education and support opportunities, but also to raise and provide funds to support IBD research. To serve the less densely populated areas of the country, CCFA offers an online support forum for members to share information and experiences. To promote a greater sense of community, CCFA may benefit by allowing members to segregate themselves into regions, states, or areas, as illustrated by the MontanasGotGuts community. Study participants valued the Montana-only community, and expressed a sense of belonging and the perception of support as part of a geographically close community. By allowing “community” groups within the forums, whether by state, city, or even a college campus, this same sense of belonging, and increased perceptions of support, may be fostered among its members.

### Those with IBD

While membership in the MontanasGotGuts online community has continued to steadily increase, active participation by its members is still lagging. And, while participants in this study recognized that they needed to contribute more to make the community a success, they were still hesitant. Community members need to be reassured that their presence in the community is valued, and that whatever contributions they may make are welcome and appreciated. Most members joined because they want to hear the experiences of others, and want to help. Everyone's experiences are valid and appreciated. And, anyone who does contribute needs to get immediate and positive feedback from the community. Providing help and support to others can be even more beneficial than receiving it.

### IBD Physicians and Healthcare Professionals

The purpose of this study was to demonstrate to local IBD healthcare professionals how beneficial this community could be to those it serves. As the initial, and most influential, providers of information and support to those in Montana with IBD, it was imperative that they not only see the online community as a successful provider of support, but that they also recommend it to their patients. The relationship between the online community and the healthcare community must be seen mutually beneficial. As demonstrated by the continued growth in the community's membership, those in Montana with IBD are in search of something that they do not or cannot receive from the traditional healthcare community. As a result of this study, it is hoped that those healthcare professionals who have supported and recommended the online community

continue to do so, and that more healthcare professionals in Montana see the benefits the community can bring their patients.

#### Online Health Community Administrators

Some lessons learned in this study may benefit in the development and administration of other online health communities, especially those that serve relatively smaller and lesser-known populations such as IBD. Maybe most importantly, administrators must never assume that the membership is not “participating” just because that participation is not seen. Many members will visit the website, read the articles and comments, but never leave comments or engage in dialog with other members. Even those who passively participate, the lurkers, may benefit greatly as a member of the community. It is essential that website analytics are available to monitor and identify all website traffic, and that the administrator not depend solely on visible contributions.

A great deal of patience is required throughout the creation and infancy of any online community, and this is even more crucial when dealing with an illness such as IBD. In this study, participants displayed a great reluctance to participate, and expressed feelings of shyness and a reluctance to exhibit a “poor me” persona. It is up to the community administrator to set an example for the membership, to share of himself or herself, to recognize and show appreciation for those who do contribute, and to provide immediate and positive feedback. The administrator must continually encourage and foster participation, while at the same time establishing the community as a safe and welcoming place.

The Montana-only aspect of this website allowed members to develop a sense of belonging and sense of community that may not be experienced in other online communities. Living in Montana was considered a unique experience to the members of this community. Furthermore, many participants expressed an “us against the world” attitude, and felt somewhat overlooked or ignored by the national organization. Therefore, it may be difficult to recreate the sense of community displayed by participants in this study within other online communities. It may benefit administrators of other online health communities to identify and promote unique characteristics of their own community that may allow members to develop a stronger sense of community.

#### Limitations of the Study

1. Participation in the online community, and consequently the study sample, consisted of volunteers -- only those who are interested in participating in an online support community, gaining social support and information, and interacting with others. Such individuals may have a predilection for information seeking and participating in social support activities.

2. The study assessed participants’ experiences in the online community at a point in time early in the existence of the community. Those who join the community at a later time, when the membership might be larger, may benefit from a larger community in which to interact.

3. The study participants needed access to a computer and an Internet connection on a regular basis. Thus, the study sample excluded those without access.

### Suggestions for Further Research

This study provides ample opportunities for further research concerning online communities and social support.

1. Why do people join illness-related communities? The participants in this study were asked why they joined the online community. Many stated that it was to get more information about IBD while others said it was to meet other people with IBD. If more were known about why people join and what their preconceived ideas were about the community, what they wanted from the community, and what they expected to gain, better efforts could be made to provide exactly what they want.

2. Can community members who initially meet online develop strong relationships offline if given opportunities? One of the goals of the online community in this study was to provide the opportunity to meet others who may live in the same area. This was seen on a very limited basis as one offline event, not associated with the online community, did allow some members to meet face-to-face. Follow-up studies may help to discover how beneficial these online/offline relationships are. Additionally, if more offline events were available, how inclined would community members be to participate?

3. How beneficial are the information and knowledge gained through the online community? Do members want information just for the sake of having more information, or do they make use of the new information they find? A more in-depth look at information seeking as a coping mechanism, the flow of information, what kind of information is wanted, which sources are most valued, and how recipients use this information would be a worthwhile follow-up study.

### Chapter Summary

The purpose of this descriptive study was to discover how individuals participating in a Montana-specific, online support community for those in Montana with inflammatory bowel disease (IBD) assess and describe their experiences within the community, and how they report that their experiences have affected their health-related quality of life (HRQOL) in the areas of social support and illness knowledge.

Although the level of active participation in the website by members was low and not anticipated by this researcher, the concept of perceived support was seen to successfully impact the social support levels of many participants. In addition, participants reported increases in information support as a result of participating in the community. The findings of this study demonstrate that this online community can be a viable option for social support and IBD-related knowledge for those in Montana with IBD. This, in turn, can lead to positive impacts on the HRQOL of its members.

Chapter 5 presented an overview of this study and the answers to the research questions posed in this study. The findings of this study were compared to the literature, recommendations were made, and suggestions for further research were also presented.



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APPENDICES

APPENDIX A

OVERVIEW OF POPULAR ONLINE IBD SUPPORT WEBSITES

Appendix A

Overview of Popular Online IBD Support Websites

Website	Sponsor/ Admin	Purpose	IBD Specific	Members & Activity	Searchable by State
Crohn's Disease Forum [crohnsforum.com]	IBD patient	Support forum only	Yes	10,000+ members high activity	Yes <sup>1</sup>
IBD Support Group [ibdsupport.org]	Mediboard Privately-held	Support forum only	Yes	4,600 members high activity	By country only
CCFA Community [ccfacommunity.org]	Commercial CCFA Abbott	Support forum & information	Yes	10,000+ members high activity	Member location not available
Daily Strength [dailystrength.com]	ShareCare	Support forum & information	No – part of multi- illness platform	3,700 members high activity	Yes
WebMD [webmd.com]	Commercial	Support forum & information	No – part general health platform	6,000 members high activity	Member location not available
Healing Well [healingwell.com]	Commercial	Support forum & information	No – part general health platform	143,000 members # of IBD members unknown high activity	Member specifics not available
Crohn's Zone <sup>2</sup> [crohnszone.org]	IBD patient	Support forum only	Yes	4,000 members low activity	Yes
Patients Like Me [patientslikeme.com]	Commercial	Support forum & information	No	200,000+ members 2,000+ IBD members <sup>3</sup> high activity	Yes

<sup>1</sup>The ability to search by state is a relatively new feature added in 2013.

<sup>2</sup>This site touted large activity numbers in the past, but as of late 2013 activity has decreased substantially.

APPENDIX B

MONTANASGOTGUTS.ORG WEBSITE SCREENSHOTS

# MontanasGotGuts.org

Montana Crohn's & Colitis Information & Support Community



- HOME
- MEMBERS
- MAP
- BLOGS
- DISCUSSIONS
- EVENTS
- MY PAGE
- CHAT
- FAQ
- PHOTOS
- RESOURCES

ADMIN

### IBD in the News

How important is vitamin D for treating Crohn's disease and colitis? - eMaxHealth

Martini Madness to benefit Crohn's and Colitis Foundation - InsideHalton.com

Why are Crohn's disease and colitis such mysteries? - eMaxHealth

Why Crohn's disease can cause mouth problems - eMaxHealth

Athersys, Inc. (ATHX): Athersys-Pfizer Investors: Anticipating A Phase III ... - Seeking Alpha

More...

### Get Started!



Ask Questions. Get Answers. Help Others.

Get help and advice or share your expertise with others in the [discussions](#).

### MJ Nehasil

Sign Out

- Inbox (1 new)
- Friends - Invite
- Settings

### Events

+ Add an Event

### Photos



+ Add Photos View All

### Members

### Latest Activity

What are you up to?

MJ Nehasil left a comment for Kathryn Comer-Tuss

"Hi Kathryn! I'm so glad you did find the website! How did you find it? I think you're..."

yesterday

### Discussions

#### New Treatments on the Horizon in 2014

Started by MJ Nehasil in IBD Research & News Jan 17.

0 Replies 0 Likes

Here's a short video with three of the most prominent IBD physicians talking about what we can expect as far as new therapies in 2014. The most notable thing is that there will be new treatment classes beyond what we have now -- drugs other than the...

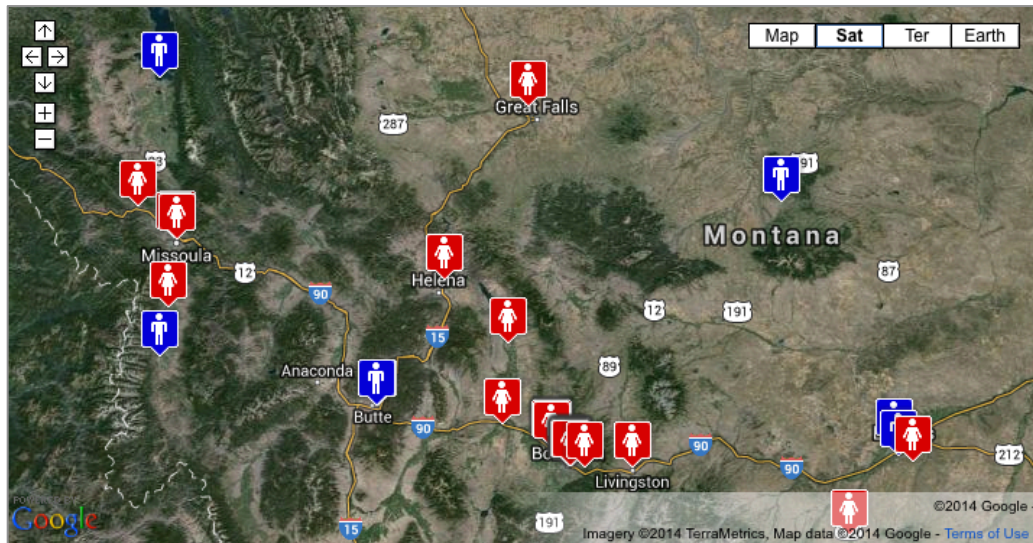
Continue

Tags: pediatrics, 2104, trials, transplant, fecal

#### Running Half Marathon

Started by O'Connor, Chris in Let's Talk about IBD. Last reply by Jodie DeLay Jan 15.

12 Replies 0 Likes



APPENDIX C

PARTICIPANT RECRUITMENT EMAIL



First of all, I want to thank you for joining the MontanasGotGuts.org online community!

The reason I'm writing to you today is to ask for your assistance. I'm in the final stages of completing my dissertation in the Department of Education at Montana State University, and am asking you to be a participant in my research study. You can read a summary of the study and what your participation would entail below. Your input can be very valuable to the study, whether you've visited website often, or you've only had minimal interaction with the website. As I state in the summary, it will take no more than an hour of your time and can be completed at a time and place of your convenience.

Please read the summary below. If you choose to participate in the study, please notify me by replying to this email.

**Thank you so much for your cooperation!**

### **Summary of the Research Study**

You are being asked to participate in a research study that examines your experiences with and assessment of the MontanasGotGuts.org online community. This study may help us to better understand the effectiveness and benefits of online communities with regards to those with inflammatory bowel disease. You have been identified as a possible subject through your membership in the online community.

Participation is voluntary! If you agree to participate in this study you will first complete a short (5-10 minute) online survey that will address a) your Internet usage, b) website usefulness and usage, c) your interactions with the website, d) your overall assessment of the website, and e) general demographic data about yourself. After you complete the survey you will be asked to participate in a 30-60 minute interview. I will ask you questions about your experiences using the online community. The interview will be recorded using a digital voice recorder, or, using audio recording software if the interview is via the Internet. All data collected will be kept confidential!

If you agree to participate in this study I will send you a link to the online survey. When you complete the survey we will arrange a time and place to meet, at your convenience, to conduct the interview.

If you have any questions please do not hesitate to contact me at (406) 551-3117, or <mailto:nehasil@brenan.net>.

*MJ Nehasil  
Bozeman, MT*

APPENDIX D

MONTANASGOTGUTS.ORG PARTICIPANT SURVEY

## MontanasGotGuts.org Participant Survey

---

### SURVEY CONSENT FORM

**SUBJECT CONSENT FORM  
FOR  
PARTICIPATION IN HUMAN RESEARCH  
MONTANA STATE UNIVERSITY**

Health-Related Quality of Life Outcomes of Participants in a Montana-Specific, Online Support Community for People in Montana with Inflammatory Bowel Disease

You are being asked to participate in a research study that examines your experiences with and assessment of the MontanasGotGuts.org online community. This study may help us to better understand the effectiveness and benefits of online communities with regards to those with inflammatory bowel disease. You have been identified as a possible subject through your membership in the online community.

Participation is voluntary! If you agree to participate in this study you will first complete a short online survey that will address a) your Internet usage, b) website usefulness and usage, c) your interactions with the website, d) your overall assessment of the website, and e) general demographic data about yourself. After you complete the survey you will be asked to participate in a 30-60 minute interview. I will ask you questions about your experiences using the online community. The interview will be recorded using a digital voice recorder, or, using audio recording software if the interview is via the Internet. The recording will be transcribed, verbatim, by the interviewer. Only I, Mary Jo Nehasil, will have access to the recordings from the interview. These tapes will be erased no later than 30 days from the completion of my degree. I may also contact you at a future date to clarify questions or to provide insight into my interpretation of the data.

Participation is voluntary and you can choose to not answer any questions you do not want to answer and/or you can stop at anytime. You may ask me about the research procedures and I will answer your questions to the best of my ability. Your participation in this research study is confidential. Following our initial conversations, I will identify you using a code number. I will be the only person with access to the key linking your name with this code number. Results of this study will be reported using pseudonyms. Although there are no foreseen risks, if I believe that information from your survey or interview could result in you or your family being uniquely identifiable, I will decline to disclose this information.

This study is of no direct benefit or cost to you. If you have any questions regarding this research project you can contact me, Mary Jo Nehasil, the investigator for this study, at (406) 582-1860, or [nehasil@montana.edu](mailto:nehasil@montana.edu). Any additional questions about the rights of human subjects may be directed to Dr. Mark Quinn, chair of the MSU Human Subjects Committee, at (406) 994-5721 or [mquinn@montana.edu](mailto:mquinn@montana.edu).

*Please print this page for your own records.*

**AUTHORIZATION: I have read the above and understand and agree to the conditions, potential inconveniences and risks of this study as described. I agree to participate in this research. I understand that I may later refuse to participate and that I may withdraw from the study at any time. I have received a copy of this consent form for my own records.\***

**Yes**

**No**

---

## **SURVEY SUMMARY**

This survey consists of the following four components. The first section asks questions about you, your background, and your illness. The second section asks about how you use and interact with the the Internet, and the MontanasGotGuts.org website. The third section asks about your experiences using the website, and how your participation has affected you. The final section asks about your overall experience with the website. Your answers will be kept confidential.

Participation is voluntary, and you can choose to not answer any question that you do not want to answer, and you can stop at anytime. Completion of this questionnaire implies that you have read the informed consent document and consent to participate in this study.

**Thank you again for participating in this study!**

---

## **WHO ARE YOU?**

1) What is your gender?\*

Male

Female

2) How old are you?\*

- Under 18
- 18-30
- 31-40
- 41-50
- 50-60
- Over 60

3) What city do you live in?\*

4) What is your household status?\*

- Live alone
- Do not live alone

5) What is your highest level of education?\*

- Some high school
- High school graduate/GED
- Some college
- College graduate
- Graduate degree

6) Which type of IBD do you have?\*

- Crohn's disease
- Ulcerative colitis
- Other: \_\_\_\_\_\*

7) How long have you been diagnosed with IBD?\*

- Less than a year

- 1-2 years
- 3-5 years
- 5-10 years
- 10-20 years
- More than 20 years

8) With regards to your IBD, how would you rate your current health?\*

- Excellent
- Very good
- Good
- Fair
- Poor

9) In the past three months, how often has your IBD limited you from carrying out your normal activities (work, school, social events, household chores)?\*

- Every day
- Most days
- Once in a while
- Rarely
- Never

---

## **WEBSITE USAGE & USEFULNESS**

### **Website Usage**

10) Before using this website, how often did you use the Internet?

This includes using email, visiting other websites, online banking, entertainment, etc.\*

- Several times a day

- About once a day
- Several times a week
- About once a week
- Several times a month
- Less than once a month
- Did not use the Internet

11) How often, on average, do you visit this website?\*

- Several times a day
- About once a day
- Several times a week
- About once a week
- Several times a month
- Less than once a month

12) How long, on average, is each visit to this website?\*

- Longer than one hour
- 30 minutes to one hour
- 10 to 30 minutes
- Less than 10 minutes

13) How often do you post messages or comments on this website?\*

- Every day
- Several times a week, but not every day
- About once a week
- Less than once a week
- Never

## Website Usefulness

14) Please rate the usefulness to you of each area of the website.\*

	Extremely Useful	Very Useful	Somewhat Useful	Slightly Useful	Not at all Useful
Forums	( )	( )	( )	( )	( )
Member Profiles	( )	( )	( )	( )	( )
Member Map	( )	( )	( )	( )	( )
Member Blogs	( )	( )	( )	( )	( )
Activity Stream	( )	( )	( )	( )	( )
News & Research	( )	( )	( )	( )	( )
Event Calendar	( )	( )	( )	( )	( )
Online Chat	( )	( )	( )	( )	( )
Private Messaging	( )	( )	( )	( )	( )
Photo Gallery	( )	( )	( )	( )	( )



15) Please rank this online community as compared to other support and information resources that may or may not be available to you.\*

\_\_\_\_\_ MontanasGotGuts.org Website

\_\_\_\_\_ Physician

\_\_\_\_\_ Nurse

\_\_\_\_\_ Family

\_\_\_\_\_ Friends

\_\_\_\_\_ Others with IBD (who are not members of this community)

\_\_\_\_\_ Internet (professional websites and other online forums)

\_\_\_\_\_ Books or pamphlets

\_\_\_\_\_ Professional journal articles

---

## COMMUNITY PARTICIPATION EXPERIENCE

16) Through my participation in the MontanasGutGuts.org online community ...\*

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I understand my illness better.	( )	( )	( )	( )	( )
I feel I have more access to knowledge about my illness.	( )	( )	( )	( )	( )
I can better understand the information provided to me by my physician.	( )	( )	( )	( )	( )
I am better able to judge when I really need the help of my physician.	( )	( )	( )	( )	( )
It is easier for me to tell others when I am	( )	( )	( )	( )	( )

not able to do something.					
It is easier for me to ask others for help.	( )	( )	( )	( )	( )
I know more about where to go with questions about my illness.	( )	( )	( )	( )	( )
I feel more able to make the better decisions with regard to my illness.	( )	( )	( )	( )	( )
I feel more in charge of the course of my illness.	( )	( )	( )	( )	( )
I have more faith in my future.	( )	( )	( )	( )	( )
I have a more positive attitude towards	( )	( )	( )	( )	( )

myself.					
I am generally more content with my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel less lonely.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have made new social contacts.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

## OVERALL WEBSITE EXPERIENCE

17) In general, how satisfied/dissatisfied are you with your experiences in the MontanasGotGuts.org online community?\*

- Very dissatisfied
- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- Very satisfied

18) What has been your most positive experience with the MontanasGotGuts.org online community?\*

19) What has been your least positive experience with the MontanasGotGuts.org online community?\*

20) Please provide any additional feedback you'd like to give.

---

**Thank You!**

**Thank you again for participating in this study!**

You will be contacted shortly by the researcher to set up a time and place for a one-on-one interview. The interview will last approximately 30-60 minutes and can be in person, over the the telephone, or online via Skype, Google Hangout, etc. – whichever is most convenient for you.

If you have any questions please contact the researcher at (406) 582-1860 or [nehasil@bresnan.net](mailto:nehasil@bresnan.net).

APPENDIX E

PARTICIPANT INTERVIEW QUESTIONS

## MontanasGotGuts.org Participant Interview Questions

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### Interview Questions

1. Why did you join the online community?
2. Have your expectations been fulfilled? Why or why not?
3. What has been the most helpful and/or useful aspect of the community?
4. What has been the least helpful and/or useful aspect of the community?
5. How has participation in the online community impacted the amount of support you receive regarding your illness?
6. How has participation in the online community impacted your knowledge about your illness?
7. What, if anything, would increase your participation in the community? (site features, technology, content, etc.)
8. What, if anything, is preventing or hindering you from greater participation in the community?
9. Do you think having a “Montana-only” community is beneficial to you? Why or why not?

APPENDIX F

MONTANASGOTGUTS.ORG POSTER



Do you have **CROHN'S DISEASE** or **ULCERATIVE COLITIS** and live in Montana?

*Then this website is for you!*



**MontanasGotGuts.org**  
*Montana Crohn's & Colitis Information & Support Community*

MontanasGotGuts.org is a new online community to help people in Montana who have Crohn's Disease or ulcerative colitis find others who have these diseases — to share their knowledge and experiences, and to offer support to one another. You might even find someone right in your own neighborhood!

Ultimately, the goal of MontanasGotGuts.org is to establish a permanent and easily accessible resource and support network throughout Montana — a place where there's always someone available to offer information and advice ... or to just listen.

**Join Today! It's easy! Just visit [montanastgotguts.org](http://montanastgotguts.org) to register.**

<http://montanastgotguts.org>

October 2011

[mj@montanastgotguts.org](mailto:mj@montanastgotguts.org)