

ENGAGEMENT IN ONLINE HEALTH COMMUNITIES:  
EXPRESSED ATTITUDES AND SELF-EFFICACY OF  
ARTHRITIS SELF-MANAGEMENT BEHAVIORS

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by

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The undersigned, appointed by the dean of the Graduate School, have examined  
the dissertation entitled:

ENGAGEMENT IN ONLINE HEALTH COMMUNITIES:  
EXPRESSED ATTITUDES AND SELF-EFFICACY OF  
ARTHRITIS SELF-MANAGEMENT BEHAVIORS

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A candidate for the degree of Doctor of Philosophy,

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## DEDICATION

To my parents, Troy and Jan, who inspire me.

To Jason, my heart.

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**ABSTRACT**

The purpose of this research is to examine the computer-mediated communication within online health communities to understand the role engagement plays in eHealth literacy and the perceived benefits, perceived barriers, and expressed feelings of self-efficacy toward self-management behaviors of people with arthritis. This study used two methods: content analysis, and concurrent ethnomethodology. A four constructed-week sample was collected from four online health communities for the content analysis (N=1,960), and more than 6,500 archived posts were examined ethnomethodologically. The results indicated that online health communities facilitate self-management behaviors through the exchange of health information and/or disease experience. These online health communities act as informal self-management programs led by peers with the same chronic disease through the exchange of health information based on experience, working to improve members' health literacy related to arthritis. Online health communities provide opportunities for health behavior change messages to educate and persuade regarding arthritis self-management behaviors.

## **CHAPTER I**

### **INTRODUCTION**

The new media landscape has transformed patients into empowered consumers, making them partners in their own health and health care (Cline & Haynes, 2001). For instance, the Internet has joined doctors and family members as one of the top three sources people use to find answers to their health questions (Diaz, Griffith, Ng, et al., 2002). The Internet facilitates the exchange of health information and personal experience in a way that transcends both health care professionals and traditional social networks – yet offers some of the benefits of both (Ball & Lillis, 2001; Iakovidis, Wilson & Healy, 2004).

Communicating about health online in the form of bulletin boards, blogs and chat rooms has become popular, especially among those with a chronic disease (Kalichman, Benotsch, Weinhardt, et al., 2003). Chronic disease has been called the “silent epidemic” by the Centers for Disease Control and Prevention (CDC, 2000). Chronic diseases are affecting increasing numbers of people: 133 million Americans – almost 1 out of 2 adults – have at least one chronic disease (CDC, 2000). Chronic diseases – such as heart disease, cancer, diabetes, and arthritis – are among the most common, costly, and preventable of all health problems in the United States (CDC, 2000). Despite the amount of knowledge and numerous interventions undertaken to prevent chronic disease, chronic disease still remains the leading cause of illness, disability, and death in the United States (CDC, 2000). Self-management programs are

evidence-based health education programs that are designed to help people build self-efficacy in their ability to control disease symptoms and disease affect on their lives, like fatigue, pain, and depression (Lorig & Holman, 2003). Self-efficacy is an individual's belief in his or her ability to successfully perform a behavior (Bandura, 1994a). Self-efficacy is a key component of chronic disease self-management programs (Lorig, Lubeck, Kraines, et al., 1985); in fact, Bandura (1977) argued that for a behavior to be performed at all, self-efficacy must be present. The issue of self-management is especially important for those with chronic disease, where only the patient can be responsible for his or her day-to-day care over the duration of the illness. For most of these people, self-management is a lifetime task. Self-management programs have been shown to be effective in reducing the impact of chronic disease, yet few people participate in such programs (Lorig, 1999; Lorig, Ritter, Steward, et al., 2001). Lorig and Holman (2003) noted that despite the lack of participation in these formal disease self-management programs, patients still manage their disease on their own. However, little is known about self-management from a patient's perspective, thus the question becomes *how* do patients with chronic disease manage their disease?

For people with chronic disease, digital media offers a solution to disease management through specialized health information, social support, and psychosocial benefits (Cline & Haynes, 2001). It is estimated that one in four consumers actively participates in an online health community (Raines, 2005). Some of these online health communities are composed of individuals that share experience or disease, offering a channel for computer-mediated communication that transcends geographic location,

race, gender, age, and stigma of disability (Frost & Massagli, 2008). People with chronic health conditions are sharing their stories with each other, not just for emotional support, but for the clinical knowledge they gain from participating with like-others in an online community (Eysenbach, Powell, Englesakis, et al., 2004; White & Dorman, 2001). The facilitation of online health communities through digital media has expanded the possibilities beyond the constraints of in-person, localized contacts. Community members are linked into networks based on shared interests or disease diagnosis. When patients managing the same chronic disease share observations with each other, their collective wisdom can yield clinical insights beyond the understanding of any single patient or health care professional (Frost & Massagli, 2008). The phenomenon of online health communities has begun to change patients' relationships with their traditional touch points in health, like physicians (Eng, 2001; Goldsmith, 2000; Murray, Lo, Pollack, et al., 2003). By sharing ideas, discussing symptoms, self-management strategies, and debating treatment options together, all of these stakeholders gain knowledge that can ultimately improve patient care (Frost & Massagli, 2008).

However, health information that is exchanged online requires patients to have both a sophisticated level of health knowledge and adequate literacy skills – or, *health literacy*. Health literacy is the ability of an individual to access and understand health information and use it to better one's health (Ratzan, 2001). Although the problem remains largely invisible, millions of Americans have a hard time reading. As many as half of U.S. adults have limited literacy skills; and even a greater proportion have limited health literacy skills (Kutner, Greenberg, Jin, & Paulsen, 2006; National Center for

Education Statistics, 2003). An individual may be extremely literate and still have difficulty interpreting and acting on health information – whether it's online or in print. The Web just poses new barriers to patients, including access to and experience with the Internet, literacy skills, complexity of information online, and searching and navigational difficulties (Summers & Summers, 2004; Zarcadoolas, Blanco, Boyer, & Pleasant, 2002). Knowledge of this process of online health information seeking is called *eHealth literacy* (Norman & Skinner, 2006). People must have eHealth literacy skills in order to find accurate, useful information online, and apply it to everyday situations “off-line.” The engagement in eHealth is what motivates people to turn knowledge into action (Lefebvre, Tada, Hilfiker, & Baur, 2010), and is influenced by an individual's attitudes and feelings of self-efficacy (Bandura, 1977). Engagement is important to understanding how people use online health information, especially as engagement is influenced by health status or disease experience.

Online health communities provide rich contextual data that is produced by patients for patients in regards to chronic disease. The computer-mediated communication that is exchanged among peers is available within these online communities, allowing for researchers to take a “bird's eye view” of how patients manage their disease. Indeed, research in health communication has examined the online content found within these online health communities (Rodgers & Chen, 2005; Wright, 2000); however, little research examines online health communities for the patient's perspective of chronic disease self-management. This paper outlines a



framework for analyzing self-management behaviors in the context of computer-mediated communication within online health communities.

Specifically, this paper examines online health communities related to arthritis. Arthritis is the leading cause of disability, affecting one in five Americans (CDC, 2000). The Centers for Disease Control and Prevention (CDC, 2009) note that as the “baby boomer” population continues to age, arthritis will become even more prevalent. Arthritis is a chronic disease of the joints that requires patient self-management. Due to the unpredictability of arthritis symptoms and disease “flares,” problem-solving and decision-making skills are especially important. Understanding these processes will provide insight into how to improve self-management behaviors by people with arthritis, guided ultimately by the patients’ perspective. Untreated or inadequately managed arthritis can have a negative impact on people with the disease by limiting physical abilities, quality of life, work, and the ability to manage other chronic conditions successfully (Theis, Helmick, & Hootman, 2007). “For those with arthritis, quality of life can be improved and pain and disability decreased and delayed through participation in arthritis self-management” (Theis, Helmick, & Hootman, 2007, p. 450). Due to the large number of people with arthritis, online arthritis-related health communities need to be examined for insight on how to improve self-management behaviors, including perceived benefits, perceived barriers, and feelings of self-efficacy. Health communities are rapidly forming on the Internet, though little research examines these peer-to-peer communities in regards to their potential for health education and promotion. This research will draw from the disciplines of health care and health communication in

order to inform health education and promotion, but also to understand how new media facilitates patients' use of disease self-management.

Online health communities have the potential to offer resources that facilitate the "off-line" use of chronic disease self-management behaviors. Through peer-to-peer computer-mediated communication, online members are already exchanging information related to their chronic disease. Such insight from the patient's own perspective will allow health communication to "speak" to these patients in "their own language" about behaviors that fit their "off-line" lifestyles. There is great potential in these online health communities to encourage better health management by patients through improved health literacy.

To orient the reader, the remainder of this paper is outlined. First, a brief discussion of health literacy will ensue, as this is an underlying concept in patients' understanding and use of health information. Next, health in the new media landscape, or eHealth, will be defined and discussed in relation to the computer-mediated communication found within online health communities. These online health communities (OHCs) create an opportunity for health education and promotion, especially with regard to chronic disease and self-management (Frost & Massagli, 2008). Currently, there is no gold-standard of self-management, but several definitions are offered in the literature (see Alderson, Starr, Gow, & Moreland, et al., 1999; Barlow, Wright, Sheasby, et al., 2002; Bodenheimer, Lorig, Holman, & Grumbach, 2002; Clark, Becker, Janz, et al., 1991; Corbin & Strauss, 1988; Jerant, von Friederichs-Fitzwater, & Moore, 2005). Because so many people with arthritis have at least one other chronic

disease (CDC, 2000), self-management behaviors must be applicable to more than one disease. Thus, self-management will be defined later, including the construct of self-efficacy. Self-efficacy is a commonality within health behavior change theories and models, like theory of reasoned action or the health belief model (Bandura, 1986; Fishbein & Ajzen, 1975). Self-efficacy is especially important to chronic disease self-management (Holman & Lorig, 2004).

Finally, this study used a multi-method design to examine the issue of self-management and use of online health communities in developing, learning, and using health literacy knowledge and skills to discuss and share strategies for practicing self-management. A content analysis was conducted to understand the types of self-management behaviors that are being discussed online, and to examine patients' discussions of these behaviors for evidence of their perceived benefits, perceived barriers, and feelings of self-efficacy regarding particular self-management behaviors. Additionally, the content analysis is used to determine whether a relationship exists between engagement in online health communities and self-management strategies and outcome behaviors.

The second study was a simultaneous ethnomethodological observation to examine the computer-mediated communication of self-management behaviors within arthritis-related online health communities. Ethnomethodology involves finding order in the concrete, not the abstract (Watson, 2009). This ethnomethodological observation allows for specific knowledge as to patients' perceptions regarding the benefits and barriers to arthritis self-management. Already, barriers to self-management have been

identified to attending formal arthritis self-management programs (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Brady, Kruger, Helmick, et al., 2003); yet, research has not examined the patient perspective of disease self-management to understand the complexities of dealing with a chronic disease. Because these online health communities provide a community of networked members with the same disease diagnosis, the exchanged computer-mediated communication gives intimate detail as to how people with arthritis perceive self-management behaviors. Ethnomethodology eliminates the social expectations and threats other social science research methods might pose to reliability. Combined, these two methods provide a better understanding of the information exchanged within online health communities by patients regarding self-management behaviors.

## CHAPTER II

### LITERATURE REVIEW

#### ***Health Literacy***

Health literacy is the ability to understand health information and to use that information to make good decisions about one's own health and health care (Ratzan, 2001). Simply, health literacy is the intersection of health and literacy. Here, health literacy serves as a "backdrop" to this research. While not directly examined, health literacy is important with regard to online information seeking. For instance, health information can overwhelm even people with advanced literacy skills. Literacy skills refer to an individual's ability to read, write, understand numeracy, and communicate effectively (CDC, 2000). Literacy skills are fundamental to understanding health and one of the key components of health literacy. About one third of the adult population in the United States has limited health literacy (CDC, 2000). This means that these patients have difficulty understanding instructions from health care professionals and reading labels on prescription bottles. Recent research has brought attention to the potential role of health literacy in influencing the inequalities of health care and health outcomes (see DeWalt, Berkman, Sheridan, Lohr, et al., 2004; Nielson-Bohlman, Panzer, & Kindig, 2004; Paasche-Orlow & Wolf, 2007; Pignone, DeWalt, Sheridan, Berkman, et al., 2005). According to the American Medical Association, "poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race" (American Medical Association Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999, p. 552). Studies show that adults with low health

literacy have less health-related knowledge, have difficulty managing their chronic disease, and are less likely to receive health services, but more likely to be hospitalized (Baker, Gazmararian, Williams, Scott, et al., 2002; Gazmararian, Williams, Peel, & Baker, 2003; Paasche-Orlow, Gazmararian, Nielson-Bohlman, & Rudd, 2005).

As a solution to improve health literacy some research has begun to focus on basic literacy skills such as reading and understanding health information by patients (Greenberg, 2001; Kutner, Greenberg, Jin, & Paulsen, 2006; Ratzan, 2001). Focus on patients' understanding of information led government organizations to use "clear communication" as the dominant strategy for improving the publics' understanding of health (CDC, 2000; National Institutes of Health, 2010). To achieve patient comprehension, health care professionals were urged to provide information content that is accessible to specific audiences based on cultural competence and also incorporate plain language (CDC, 2000).

However, this strategy of "clear communication" has not yet translated to the Internet and health information available online (Eysenbach & Kohler, 2002; Silence, Briggs, Harris, & Fishwick, 2007). Additionally, many definitions of health literacy do not take into account the influence of digital media in patients' understanding of health (Willis, Wang, & Rodgers, in press). For the purpose of the proposed research, health literacy acts as the underlying basis for which computer-mediated communication of self-management behaviors is exchanged within online health communities. To define health literacy in the context of digital media and computer-mediated communication,

several definitions from the literature are adapted to accommodate the context of online health information seeking.

For instance, the National Library of Medicine (2004) defines health literacy as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” This definition has been widely adopted, yet does not acknowledge interactive resources like the Internet and digital media. More recent adaptations of the definition of health literacy, however, include multi-dimensional domains that provide flexibility given that an individual’s understanding of health literacy evolves over time based on personal experience, including health status, demographic, sociopolitical, psychosocial, and cultural factors (Nutbeam, 2000; Zarcadoolas, Pleasant, & Greer, 2005). For example, Nutbeam (1998) defines health literacy in the context of health outcomes:

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health (p. 264).

Nutbeam (2000) recognizes the psychological, social and environmental factors that influence attitudes and behaviors related to health. He identified three domains of health literacy: *basic/functional literacy*, *communicative/interactive literacy*, and *critical literacy* (Nutbeam, 2000). “Basic/functional literacy” refers to one’s ability to read, write and communicate effectively. “Communicative/interactive literacy” is the ability to extract information and derive meaning from different forms of communication, and to apply new information to changing health circumstances. Finally, “critical literacy” is one’s ability to critically analyze health information and use it to exert greater control

over life situations (Nutbeam, 2000). Similarly, Zarcadoolas, Pleasant, and Greer (2006) defined health literacy as follows:

Health literacy is the wide range of skills, and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health and environmental information and concepts to make informed choices, reduce health risks, and increase quality of life (p. 120).

Four domains of health literacy are identified in the literature, including

*fundamental literacy, science literacy, civic literacy, and cultural literacy*

(Zarcadoolas, Pleasant, & Greer, 2005). “Fundamental literacy” includes one’s skill to read, write, understand numeracy, and communicate. “Science literacy” is one’s knowledge of scientific concepts, including scientific processes. “Civic literacy” enables people to become aware of public issues, to participate in critical dialogue, and to become involved in decision-making processes. Lastly, “cultural literacy” is the ability to recognize, understand and use the collective beliefs, customs, world-view and social identity to interpret and act on health information (Zarcadoolas, Pleasant, & Greer, 2005).

These multi-dimensional definitions are useful in thinking about health literacy in the context of digital media. The present study defines health literacy using the definitional domains proposed by Zarcadoolas, Pleasant, and Greer (2005) – *fundamental literacy, science literacy, civic literacy, and cultural literacy* – with the addition of one of Nutbeam’s (2000) domains:

*communicative/interactive literacy*. This definition provides a framework for understanding that health literacy is much more than understanding health information; instead, health literacy is influenced by a variety of external factors,



including the social environment and even, engagement in eHealth. This approach to health literacy considers the context in which people make health decisions, including the Internet and social networks that determine how health information is understood and used. Examining health behaviors provides information regarding patients' use of online health communities to manage their disease, but also strategies to improve their attitude and self-efficacy regarding self-management behaviors. Health literacy within these online health communities is context-specific and related to a particular chronic disease diagnosis – *arthritis*.

### ***eHealth***

Health in the new media landscape has been called “eHealth,” which Eng (2001) defines as “the use of emerging information and communication technology, especially the Internet, to improve or enable health or health care” (p. 20). The Internet offers sophisticated health information and the ability to retrieve it instantaneously but also enables anonymity and convenience in accessing this information (Korp, 2006). For example, 83% of Internet users reported looking online for health information (Pew Internet & American Life Project, 2010). Online searches for specific diseases and treatments were the most popular searched-for topics, but the topics with the greatest growth included seeking information about doctors and hospitals, experimental treatments, health insurance, medicines, fitness, and nutrition (Pew Internet & American Life Project, 2010). Online searches for health information are often motivated by a disease diagnosis or desire for treatment information; more than 90% of

online searches are related to physical illness (Pew Internet & American Life Project, 2010). Fox (2008) suggests that it is not only convenience that draws users to online health information seeking, but the positive experiences they have from the application of the information and the results of such health knowledge in their “off-line” worlds. Online health information seeking has yielded encouraging results and most people report that they or someone they know have been helped in one way or another by online health information (Pew Internet & American Life Project, 2010).

Keeping this in mind, it is important to consider the role of mass communication in shaping one’s health literacy (Willis, Wang, & Rodgers, in press). Much research exists in both the academic and medical literatures concerning health literacy and health communication, however little research has emerged in regards to health literacy and the Internet, or eHealth literacy. Norman and Skinner (2006) define eHealth literacy as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” (p. e9). This definition of eHealth literacy also includes six core “literacies”: *traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy*.

eHealth literacy recognizes the complexity of communication technology and the skills necessary to navigate the Internet, but also shares similar “literacies” as other scholars’ definitions of health literacy. For instance, basic literacy is a component of both Nutbeam’s (2000) and Zarcadoolas, Pleasant, and Greer’s (2005) definitions. Zarcadoolas and her colleagues identify the importance of *science literacy*, and include

*media literacy* in their *cultural literacy* domain. Nutbeam's *communicative/interactive literacy* domain encompasses the search for online health information, including the need for *computer literacy*. Therefore, online health information seeking is related to eHealth literacy, as it is a specific skill needed to access health information about a specific disease or health topic. These multi-dimensional domains of literacies work together to create a complete understanding of health.

eHealth literacy “aims to empower individuals and enable them to fully participate in health decisions informed by eHealth resources” (Norman & Skinner, 2006, p. e11). The interactive characteristics of health literacy and eHealth literacy assume the patient is a viable partner in health care, motivated to seek information from various sources and willing to participate in health care, including practicing self-management behaviors. Current research examines the potential of the Internet to deliver self-management interventions to people with arthritis (Lorig, Ritter, Laurent, & Plant, 2006; 2008; van den Berg, Ronda, Peeters, et al., 2007), but little research considers that these patients are already using the Internet to facilitate self-management behaviors. Online health communities provide a network of members with similar experience and most often, a common disease diagnosis. These communities offer patients with arthritis specialized health information and experience from other patients, and include social support and psychosocial benefits (Rodgers & Chen, 2005; White & Dorman, 2001; Wright, 2002). However, little research examines the exchanged health information within online health communities to understand how self-management is approached by patients with arthritis, and the potential role other

online community members have in influencing attitudes and feelings of self-efficacy related to self-management behaviors.

### ***Online Health Information Seeking***

The Internet facilitates crucial components of health care delivery, including patient education, disease management, clinical decision support, physician/patient communication, and administrative efficiencies (Ball & Lillis, 2001). There are three main ways of accessing online information: (1) searching for health information, (2) participating in an online community, and (3) interacting with health care professionals (Benigeri & Pluye, 2003). With so many eHealth options that offer health-related services (e.g., information, diagnosis/prognosis, support), health-related content has never been so easy to access. This proliferation of information has contributed to a changing process of knowledge sharing and dissemination in the fields of health and medicine (Benigeri & Pluye, 2003).

Scholars argue that seeking online health information is part of being an empowered patient (Henwood, Wyatt, Hart, & Smith, 2004; Iakovidis, Wilson, & Healy, 2004). Patients have access to resources from a variety of voices representing diverse viewpoints, which allows them to have information that they need to make informed health decisions (Tang & Lee, 2006). Health information available in online health communities is exchanged by patients with the same disease diagnosis, but all have very different experiences regarding living with and managing chronic disease (Frost & Massagli, 2008). People tend to trust others similar to themselves more than authority figures from business, government, and media (Edelman Trust Barometer, 2008).

Furthermore, health seekers often use the information they find online in discussions with health care professionals, to request a particular prescription drug or stimulate conversation (Al-Shammary, Awan, Butt, et al., 2007; Delic, Polasek, & Kern, 2006; Dolan, Iredale, Williams, et al., 2004; Morahan-Martin, 2004). The current health condition of Internet users (e.g., disability, present state of health, a new diagnosis, general health awareness) is identified as a significant motivation for online health information seeking (Bundorf, Baker, Singer, & Wagner, 2004; Goldner, 2006; Morahan-Martin, 2004). In fact, the sick and disabled use the Internet more frequently than people in good health (Goldner, 2006). Additionally, Bundorf et al. (2004) point to lack of insurance or underinsurance as a factor that motivates online information searches. Delic and colleagues (2006) suggest that most people seek online health information after a diagnosis to learn more about disease symptoms and available treatments. Additionally, people seek online health information to fill information gaps in health care often left by busy health care providers. Patients may not have enough time with their physician after a disease diagnosis to ask thoughtful questions. Thus, the accessibility of the Internet allows patients to seek information to answer these health questions (Delic, Polasek, & Kern, 2006).

Information is available and the patient is in control in the new media landscape. Not only do people search for health information, but many people generate their own online content (Eng, 2001). Online health information is often offered in the form of patient experiences (Eng, 2005). Bury (2005) calls people with chronic disease “expert

patients” and notes that patient experience influences disease management. Expert patients are defined by Jones (2003):

People who understand that the quality of their lives is primarily up to them; believe they can exert significant control over their own lives; are determined to have a healthy life despite their chronic condition; are realistic about the impact of their disease; and have worked out what services exist and how they can be accessed (p. 23).

Health and quality of life come from genetic inheritance, from lifestyles, and from the interventions of health care (Clayton, 2003). There has been a shift in attitude and practice for health care professionals; a shift away from knowledge and toward communication, from decision-making to decision choice. For patients choice means greater personal responsibility, a requirement to become active rather than passive in the pursuit of personal health and quality of life (Clayton, 2003).

This recent development in health care is largely due to the fact that new communication technologies provide low-cost access to health communication, with the added advantage of bringing together communities to share information and resources (Banerjee & His-Shi Leong, 2006). Additionally, Lewis (2006) points out that health issues are being discussed in terms of patient management. The general health discourse is about promoting an empowered, self-aware patient as “essentially self-managing and self-monitoring” (Lewis, 2006, p. 521), meaning the patient willingly claims responsibility for maintaining his or her health. Therefore, it is imperative in the field of health care to study the opportunities and challenges that the current eHealth landscape provides. However, little research examines the health information exchanged within online health communities in the context of computer-mediated communication.

The current research examined online health information seeking from a patient's perspective, by observing the computer-mediated communication within online health communities and examining the communication of self-management behaviors. It is important to understand the information patients are finding within these online health communities, especially if such information is influential in community members' "off-line" behaviors. Therefore, the following research question that guided this research is as follows:

**RQ1: How are online health communities being used by patients with chronic disease to facilitate self-management behaviors through the exchange of computer-mediated communication?**

### ***Computer-Mediated Communication***

This research examined computer-mediated communication within online health communities in relation to self-management behaviors. Here, computer-mediated communication is the context in which these behaviors are being discussed among online health community members. Computer-mediated communication has been described as "any communication patterns mediated through the computer" (Metz, 1992, p. 3). Computer-mediated communication has also been defined as "synchronous or asynchronous electronic mail and computer conference, by which senders encode in text messages that are relayed from senders' computers to receivers" (Walther, 1992, p. 52). More recent definitions of computer-mediated communication move away from the technology and emphasize the interaction of the online members. For instance, Jones (1995) writes:

Computer-mediated communication, of course, is not just a tool; it is at once technology, medium, and engine of social relations. It not only structures social relations, it is the space within which the relations occur and the tool that individuals use to enter that space (p. 19).

Some scholars believe that the effectiveness of computer-mediated communication is limited because of the absence of audio and visual (i.e., nonverbal) cues (Dubrovsky, Kiesler, & Sethna, 1991). Varying perspectives exist within the literature on the lack of nonverbal cues in computer-mediated communication, for example: (1) the absence of nonverbal cues denies Internet users important information about other user(s), such as emotions and attitudes, which leads to less effective communication in the formation of online relationships (Burgoon, Bonito, Ramirez, et al., 2002; Kiesler, Siegel, & McGuire, 1984; Kiesler, Zubrow, Moses, et al., 1985; Weisband & Atwater, 1999); (2) people adapt to nonverbal communication by filling the messages with or by interpreting stylistic and contextual cues, information about the user, thus allowing communication to occur (Bargh, McKenna, & Fitzimons, 2002; McKenna, Green, & Gleason, 2002; Walther, 1995). Some scholars (Burgoon, et al., 2002; Kiesler et al., 1985; Weisband & Atwater, 1999) argue that computer-mediated communication transmits less social and contextual cues than face-to-face interpersonal communication which shifts attention to the task under discussion, rather than other users. Social and contextual cues are those cues that govern how people behave in particular situations. In the absence of such cues, attention is focused on the informational content that is exchanged within these online health communities. Therefore, community members “tune in” to the content and delegate more cognitive resources to understanding the task under discussion (Dutta-Bergman, 2004). It stands to reason that people with arthritis are exchanging



computer-mediated communication of self-management behaviors within online health communities; and because of the nature of computer-mediated communication, community members are paying more attention to self-management and are creating relationships based on the shared experience of managing the disease. Rice and Love (1987) note that one assumption of computer-mediated communication is that less “natural richness” exists and even less “interaction of interpersonal communication” (p. 87). However, computer-mediated communication allows users to participate more “equally.” Rice and Love (1987) note, “the lacking of nonverbal cues about physical appearance, authority, status, and turn-taking allows users to participate more equally and with more extreme affect on computer-mediated communication systems than in many face-to-face interactions” (p. 89). In fact, research suggests that computer-mediated communication facilitates critical thinking in online group discussions and peer-to-peer interaction (Tidwell & Walther, 2002). With the exponential growth of the online community, an abundance of studies have been conducted on how computer-mediated communication influences “off-line” behaviors by providing opportunities for relationship building and knowledge sharing (Bieber, Engelhardt, Furuta, et al., 2002). The current research examined self-management behaviors within the context of computer-mediated communication of online health communities. The online health community is not only the channel by which people with arthritis communicate, but also an informal health intervention that facilitates education of self-management behaviors. Thus, online health communities provide access to this exchanged health information and allow insight into how people with arthritis manage their disease.

### ***Online Health Community***

Traditionally, the word “community” has been defined as a group of people who interact and live in a common location (Hillery, 1955). Communities are often organized around common values and have social structure within a shared geographical location (McMillan & Chavis, 1986). But with the advancement of information and communication technology, geography no longer shapes communities; instead, the communication aspect is enhanced and online communities are created (Eng, 2001). Nevertheless, little consensus has been reached on basic concepts such as definitions and classifications of online communities. For example, online communities have become almost synonymous with the term virtual community, or with various forms of group-computer-mediated communication, including email-list forums, chat rooms, and Web-based discussion boards (Hagel & Armstrong, 1997). All of these terms, however, encourage community interaction and communication among members.

Rheingold (1993) defines online communities as “social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace” (p. 5). This definition has been the most widely used (Jones, 1997); however other scholars (see Boyd & Ellison, 2008; Fernback, 1999; Fernback & Thompson, 1995; Preece, Nonnecke, & Andrews, 2004; Romm, Pliskin, & Clarke, 1997) have proposed definitions. For instance, Fernback and Thompson (1995) argue that an online community must be shaped around a topic of interest. Early online communities for education (Hiltz, 1985), networked communities (Rheingold, 1993; Schuler, 1996)

and office communities (Sproull & Kiesler, 1991), were developed for community members with similar goals and experience. Other scholars' definitions focus on the computer-mediated communication (Plant, 2004; Romm, Pliskin, & Clark, 1995) or interaction (Preece, Maloney-Krichmar, & Abras, 2003) among the community's users. Referring to online communities in general, Preece and her colleagues (2003) argue the characteristics of an online community are determined by the social interactions of the members. More specifically, Muniz and O'Guinn (2001) say three characteristics help define community: shared consciousness, communal rituals and traditions, and a sense of moral responsibility. Shared consciousness is defined as "the intrinsic connection that members feel toward one another and the collective sense of difference from others not in the community" (Muniz & O'Guinn, 2001, p. 413). Rituals "are conventions that set up visual public definitions;" traditions are "social practices which seek to celebrate and inculcate certain behavioral norms and values" (Muniz & O'Guinn, 2001, p. 413). Finally, a sense of moral responsibility is the sense of obligation members feel toward the community as a whole and toward individuals in the community (Muniz & O'Guinn, 2001). These characteristics help to conceptualize online communities.

Specifically, this research examines online *health* communities, or OHCs. Much like online communities, the literature is ambiguous regarding the term online health community (OHC). However, Neal et al. (2006) offer characteristics specific to online health communities:

Online health communities provide a means for patients and their families to learn about an illness, seek and offer support, and connect with others in similar circumstances. They are supported by a variety of technologies (e.g., email lists, forums, chat rooms) and are hosted by

patients, advocacy groups, medical organizations and corporations. They raise difficult design challenges because of the wide variability of members' medical expertise, the severity of problems due to misinformation, and the need for emotional support. The importance of online health communities is evidenced by their popularity, as well as the significant impact they have on the lives of their members.

Studies of people using online health communities (Finn, 1999; Han & Belcher, 2001; White & Dorman, 2000) report the advantages of 24-hour availability of information and support from others who may be far away. Even with strong networks of support from "off-line" family and friends, patients may benefit from having an outlet of people who can relate to what they are going through on a personal level (Charmaz, 1991). Initial research on online health communities found that participation may lead to positive health outcomes, by providing referrals to other Websites through links containing information about the issue or information based on the experiences of other members (Finn, 1999; Wright, 1999; 2002). This type of informational support empowers consumers to seek additional knowledge, change health behaviors, and manage chronic disease (Cline & Haynes, 2001; Eysenbach, 2000; Pecchioni & Sparks, 2007; White & Dorman, 2001).

Communication within online health communities provide insights into the way in which consumers understand health issues, including their knowledge about certain health conditions and health literacy. Early studies show that online health communities can improve health literacy through interaction with others and the exchange of information (Kalichman, Weinhardt, Benotsch, et al., 2000). Such interactivity improves "off-line" behaviors in regards to disease management (Tate, Jackvony, & Wing, 2003; Wantland, Portillo, Holzemer, et al., 2004). For example, research shows that greater

use of the Internet for health information on HIV/AIDS correlated with greater use of coping strategies and social support (Kalichman, et al., 2000) as well as disease knowledge and self-management behaviors (Kalichman, Benotsch, Weinhardt, et al., 2002). These studies demonstrate the need to examine online health communities to understand the influence of peer-to-peer computer-mediated communication on health knowledge and behaviors. Motivations vary for participating in online health communities (Dutta-Bergman, 2006), but research demonstrates there are positive health benefits to participating (Atkinson & Gold, 2002; Eng, 2004). Although emotional support is important, it is less so than finding out what others say about a medication or treatment, researching others' knowledge and experiences, learning how to manage a condition (Cline & Haynes, 2001; Eysenbach, 2000; Pecchioni & Sparks, 2007; White & Dorman, 2001). Little research examines self-management within the context of computer-mediated communication exchanged within online health communities. This research examined self-management behaviors from a patient's perspective to understand how arthritis is managed day-to-day using the health information exchanged within these online communities.

Studies concerning online health communities have become popular in health communication across topic areas like breast cancer (Lieberman & Goldstein, 2005; Rodgers and Chen, 2005; Williamson, 2005), social support (Braithwaite, Waldron, & Finn, 1999; White & Dorman, 2001; Wright, 2000), smoking cessation (Feil, Noell, Lichtenstein, et al., 2003; Munoz, Lenert, Delucchi, et al., 2006), and weight loss (Gold, Burke, Pintauro, et al., 2007; Tate, Wing, & Winett, 2001). These studies examine peer-

to-peer online health communities and the attributes of each community. Also, there is burgeoning research of evidence-based health interventions offered online (see Oenema, Brug, & Lechner, 2001; Prochaska, Zabinski, Calfas, et al., 2000; Woodruff, Edwards, Conway, & Elliott, 2001), yet little research examines the potential of online health communities to facilitate informal self-management interventions led by patients based on personal experience of chronic disease. Because computer-mediated communication within these health communities tends to be task-oriented (Burgoon, et al., 2002; Kiesler, et al., 1985; Weisband & Atwater, 1999) and self-management is so crucial to living with arthritis (Lorig & Holman, 2003), it stands to reason that community members are exchanging health information regarding self-management behaviors, including personal experience with prescription medications, joint replacements, or weight-management, for example. How people interpret health messages largely depends on the degree to which they are engaged with the topic (Chaffee & Roser, 1986). Research of health interventions offered via the Internet guide the current study in regards to conceptualizing engagement. Due to the nature of arthritis and the unpredictability of its symptoms, arthritis self-management requires patients to be “tuned in” to their bodies and be equipped with problem-solving skills that enable them to adequately manage their disease. Thus, arthritis demands that patients be “engaged” with their disease symptoms, but also with self-management behaviors.

### ***Engagement***

Engagement is the link that connects education to action – motivating individuals beyond a state of awareness to adopt and maintain new behaviors and healthy lifestyles

(Stretcher, Seijts, Kok, et al., 1995). In regards to the current research, engagement in computer-mediated communication of self-management behaviors within online health communities facilitates “off-line” behaviors through the exchange of health information by peers. Engagement has a variety of meanings to communication researchers (see Salmon, 1986), and is often used synonymously with involvement. To differentiate these two terms, involvement refers to extrinsic motivation that spurs participation, while engagement is intrinsic motivation to participate in a behavior (Deci & Ryan, 1985; Prentice-Dunn & Rogers, 1986). Here, engagement is used to describe both the participation of community members and the way members are able to express themselves when they participate. For instance, the frequency of which community members seek or exchange health information, the content of the information exchanged both give insight into community members’ engagement with the topics under discussion within the online health community.

In online health communities, members who seek informational support are resourceful, seeking or providing information when the need arises and then withdrawing when the information need is gone (Dutta-Bergman, 2004). Although reciprocation is an important aspect of a community, there are times when a member may be too ill, or too depressed, to participate in the online health community. Similarly, there are times when members are not strong enough to reciprocate the advice they have received, and online health communities allow members to withdraw when they need to do so (Dutta-Bergman, 2004). Engagement at the individual level refers to the exchanged computer-mediated communication in ways that are often

uncommon in interpersonal communication. For instance, computer-mediated communication allows users to create messages at various times, in the absence of online community members, and provides the capability to edit messages (Walther, 1995). These technological attributes aid in the deliberate choice of words community members use as they describe difficult issues to provide insightful responses. In computer-mediated communication, recent research has documented that users take more time and edit messages more when they are addressing an audience that matters to them, making messages friendlier and more sophisticated (Walther, 1999). Online community members are still as effective in using computer-mediated communication to relay emotion as face-to-face interactions using both words and nonverbal cues (Walther, Loh, & Granka, 2005). In fact, one respondent in Walther and Boyd's (2002) study described the communication in online health communities as "a purer form of communication" than face-to-face interaction:

Writing is a lot different means of communicating that we are all used to. Our questions and answers are more articulate, more meaningful, and can be viewed over and over again until we get the message. It is my belief that the discussion is easier and healthier... (p. 180).

However, there is incongruity in the literature of the importance of engagement in eHealth to produce positive health outcomes. This research examined computer-mediated communication within online health communities to understand the role engagement plays in eHealth literacy. Thus, engagement must be defined in the context of eHealth literacy. Engagement is more than exposure to health information, but the critical thinking and problem solving skills used in decisions related to health. So then,



eHealth engagement is the process of involving users in health content in ways that motivate and lead to health behavior change (Lefebvre, Tada, Hilfiker, & Baur, 2010).

Research from Web analytics suggest online engagement is measured by unique visits, frequency of visits, recency of visits, depth of visit, and time spent on site (Danaher, Boles, Akers, et al., 2006; Danaher & Seely, 2009). These classifications are useful in tabulating engagement in the sense of frequency of participation within the online health community. However, an additional framework is necessary to identify *how* online health community members are engaging in eHealth literacy. In part, eHealth literacy is concerned with an individual's ability to identify credible and trustworthy online health information, but more important is what the individual does with the health information (Norman & Skinner, 2006). Thus, the current study also draws on Perkin and Murphy's (2006) model for identifying engagement in critical thinking in online discussions by online community members. This model includes four categories: *clarification*, *assessment*, *inference*, and *strategies*. Clarification refers to "all aspects of stating, clarifying, describing (but not explaining) or defining the issue being discussed" (Perkin & Murphy, 2006, p. 301). Assessment is to evaluate some aspect of the discussion; for instance making judgments on a situation, or providing evidence for an argument or Web links to other pertinent issues. Perkin and Murphy (2006) define inference as "showing connections among ideas; drawing appropriate conclusions by deduction or induction, generalizing, explaining (but not describing), and hypothesizing" (p. 301). Finally, strategies refer to the discussion or evaluation of possible actions (Perkin & Murphy, 2006). Because computer-mediated communication is without

nonverbal cues, the content exchanged between online community members becomes even more important. Members only have communication in which to base their knowledge sharing and relationship building (Eng, 2004). Thus, being able to identify users' engagement with the computer-mediated communication is important.

This research looked specifically at online health communities related to chronic disease self-management behaviors. Interactive features of online communities facilitate computer-mediated communication, usually concerning an aspect of living with chronic disease (Eng, 2005). In order to fully understand the role engagement plays in eHealth literacy, there must be a measure specific to online health communities. Since online health communities are created based on a common interest or shared disease diagnosis, it stands to reason that disease is the common denominator. Thus, disease stage will help to identify patterns of community members' engagement in the online health community. For example, a newly-diagnosed patient with arthritis will have different support needs than a patient diagnosed 10 years ago. Additionally, arthritis "flares" might influence engagement in the online health community. Members might seek support from other online members, including advice on symptom management. Thus, disease stage influences members' engagement in the online health community.

In summary, this research uses the following to identify engagement: frequency of visits, total number of posts, average words per post, disease stage; and the following categories related to critical thinking (Perkins & Murphy, 2006): clarification,

assessment, inference, and strategies. Based on this, the current study asked the following research question:

**RQ2: What is the type of engagement of users within online health communities; and what, if any, is the relationship between engagement and the communities examined?**

### ***Chronic Disease Self-Management***

In addition to eHealth engagement, this study examined the perceived benefits, perceived barriers, and expressed feelings of self-efficacy toward self-management behaviors of people with arthritis. Self-management programs are health education programs designed to help people gain self-confidence in their ability to control their symptoms and how their health problems affect their lives (Lorig & Holman, 2003). Research has demonstrated these programs to be effective in reducing disease symptoms (Barlow, Wright, Sheasby, et al., 2002; Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig, 1999), but yet there is no gold-standard of chronic disease self-management.

Chronic diseases have become the leading cause of death and disability in the United States (CDC, 2009). In fact, almost one in two Americans (45%) has at least one chronic disease (CDC, 2009). Co-morbidity, or multiple diagnosis of chronic disease, disproportionately affects people with arthritis, including disease diagnosis of hypertension, obesity, and diabetes, for example (Gabriel, Crowson, & O'Fallon, 1999). Arthritis is a rheumatic disease that causes pain, stiffness and swelling in the joints, and includes osteoarthritis, rheumatoid arthritis, lupus, and fibromyalgia (CDC, 2009). One in

five Americans has arthritis, making this disease the leading cause of disability in the United States (CDC, 2009). For people with chronic disease diagnosis, the goals of self-management are to enhance functional status, minimize painful symptoms, cope with the psychosocial stresses of pain and disability, and prolong life through prevention (Lorig & Holman, 2003). A diagnosis of arthritis has physical, psychological, and socio-economic implications for the patient (Dickens & Creed, 2001; Katz & Yelin, 2001; Parker, Smarr, Slaughter, et al., 2003). Since currently there is no cure for arthritis or these other chronic diseases, symptom management over the duration of disease is essential (Lorig & Holman, 2003). For effective treatment of chronic disease, the patient must participate continuously in different health care behaviors. The patient knows the most about the consequences of chronic disease and its treatments, and must apply that knowledge to guiding symptom management over time (Holman & Lorig, 2004).

In a qualitative study of people with chronic disease, Corbin and Strauss (1988) outlined three purposes of disease self-management. First, self-management includes medical management like prescription medication adherence or abiding by special diet restrictions. Maintaining, changing, and creating new life roles are also included in the purpose of self-management. The third purpose of self-management is for patients to learn how to deal with emotions that come with chronic disease. Self-management programs are designed to improve patient outcomes by helping them to understand their disease and its treatment options, increase treatment adherence, and provide patients with the knowledge and skills necessary to sustain their health (Lorig, Sobel, Ritter, et al., 2001). Research on self-management has focused on these individual

components, including the management of disease symptoms (Barlow et al., 2002; Clark, Becker, Janz, et al., 1991) and coping emotionally with chronic disease (Kralik, Koch, Price, & Howard, 2004; Newman, Steed, & Mulligan, 2004). However, most successful chronic disease self-management is dependent on a patient's ability to engage in problem-solving (Lorig & Holman, 2003). Many self-management programs include development of problem solving skills (Lorig & Holman, 2003).

Evidence-based chronic disease self-management programs are either disease-specific or general to chronic disease. Much research has been conducted on asthma (Bailey, Kohler, Richards, et al., 1999; Ghosh, Ravindran, Joshi, & Stearns, 1998; Wilson, Latini, Starr, et al., 1996), diabetes (Brown & Hanis, 1995; Glasgow, Toobert, Hampson, et al., 1992; Pichert, Synder, Kinzer, & Boswell, 1994), and arthritis (Alderson, Starr, Gow, & Moreland, 1999; Barlow & Barefoot, 1996; Lorig, Gonzalez, & Ritter, 1999; Lorig, Mazonson, & Holman, 2005) self-management interventions. In a review of self-management programs available to people with chronic disease, Barlow and her colleagues (2002) found that common components exist across these intervention programs. These include information about the disease or condition, drug and symptom management, psychological management, lifestyle factors like exercise, social support, and strategies for effective communication (Barlow, Wright, Sheasby, et al., 2002). Although these are broad categories common across self-management approaches, it is important to remember that the purpose of these programs is to help people understand their disease and use problem solving to control disease symptoms and affect on their lives (Lorig & Holman, 2003). Additionally, because so many people with

arthritis have co-morbidities, self-management behaviors must be appropriate for management of multiple chronic diseases.

Research has shown those who participate in arthritis self-management programs reduced pain by 20% and hospital visits by 40% (Lorig, Mazonson, & Holman, 2005). However, only 1 in 10 Americans with arthritis has ever participated in an arthritis self-management program (Solomon, Warsi, Brown-Stenson, et al., 2002).

Bodenheimer and his colleagues (2002) found that arthritis self-management programs have been underutilized for several reasons. First, formal arthritis self-management programs are labor-intensive and often, time-consuming. Second, many people with arthritis will not or cannot attend group education programs. Third, logistical problems make it difficult to get the patient and program together at the same time. Additionally, Brady and her colleagues (2003) noted that underutilization may be due to “misperceptions about the manageability of arthritis, previous advice not to exercise, lack of knowledge about the existence and benefits of these programs by both health care professionals and people with arthritis” (p. 59).

These barriers to participation in arthritis self-management programs led researchers to develop mail-delivered, email and Internet trial interventions (see Goeppinger, Lorig, Ritter, et al., 2009; Lorig, Ritter, Laurent, & Plant, 2008; Nour, Laforest, Gauvin, & Gignac, 2006; Stinson, McGrath, Hodnett, et al., 2010). However, these are clinical trials that are unavailable to the general population with arthritis, making in-person programs the only option for learning disease management skills. It stands to reason that people with arthritis are turning to the Internet as an option for

disease self-management intervention. This research examined self-management behaviors in the context of computer-mediated communication within online health communities, considering the following research question:

**RQ3: What arthritis self-management behaviors are discussed in online health communities; and what, if any, is the relationship between self-management and the communities examined?**

### ***Health Behavior Change***

Health behavior change theories encompass a wide scope of theories, all of which share the assumptions that health is mediated by behavior and that health behaviors have the potential for change (Elder, Ayala, & Harris, 1999). Conceptual models of behavior change, such as the theory of reasoned action (Ajzen & Fishbein, 1975), the health belief model (Becker, 1974), or social cognitive theory (Bandura, 1986), have been applied across a variety of disciplines, especially health and medicine. These prominent health behavior theories are used to predict behavior change. All of these theories share the construct of self-efficacy, which is “the belief of one’s capabilities to organize and execute the courses of action required to manage prospective situations” (Bandura, 1995, p. 2). In other words, self-efficacy is an individual’s belief in his or her ability to succeed in a particular situation. Self-efficacy influences how people think, behave, and feel (Bandura, 1994). Thus, self-efficacy is an important component to behavior change.

Self-efficacy has been applied to health behaviors and the constructs used to initiate behavior change. For example, health behaviors like smoking cessation, physical

exercise, birth control, and the use of seat belts are dependent on an individual's level of self-efficacy (Conner & Norman, 2005). Self-efficacy influences the effort an individual puts forth to change behavior and the where-with-all to continue despite barriers and setbacks that may challenge motivation. For instance, exercise has been called the "arthritis remedy" by the CDC (2009) and is also an important component to arthritis self-management. Exercise is beneficial to people with arthritis because stronger muscles help support and protect joints that are affected by the disease (Stenstrom & Minor, 2003). Participation in an exercise regime depends greatly on an individual's self-efficacy. If an individual experiences relief of arthritis symptoms due to exercise, self-efficacy is high and the likelihood that exercise behaviors will be repeated is also high. However, if an individual experiences a "flare" of arthritis symptoms after exercise, self-efficacy is low and exercise behaviors are likely not to be repeated. Self-efficacy is directly related to health behavior, but it also affects health behaviors indirectly through its impact on an individual's goals (Bandura, 2004; Rosenstock, Stretcher, & Becker, 1988; Stretcher, Seijts, Kok, et al., 1995).

Research (Lorig et al., 2001a; Lorig et al., 1999; Marks & Algrante, 2005) has shown that those who participate in self-management programs have increased self-efficacy over their chronic disease.

Health habits are not changed by an act of will. It requires motivational and self-regulatory skills. Self-management operates through a set of psychological sub-functions. People have to learn to monitor their health behavior and the circumstances under which it occurs, and how to use proximal goals to motivate themselves and guide their behavior. They also need to learn how to create incentives for themselves and to enlist social supports to



sustain their efforts (Bandura, 2004, p. 151).

Lorig and her colleagues (1999) found self-efficacy to be crucial to the success of chronic disease self-management programs. The more self-efficacy people have, the more control people believe they have over their behavior (Lorig, et al., 1999; Lorig, Mazonson, & Holman, 2005). Therefore, self-efficacy contributes to patients' problem-solving skills, motivation, and determination (Lorig, et al., 1985).

Self-efficacy is influenced by four factors: *mastery experience*, *vicarious experience*, *verbal persuasion*, and *psychological factors* (Bandura, 1994). "Performance accomplishments," or mastery experience, speaks to an individual's experience with a specific behavior. The more success an individual has with a behavior the more likely he or she is to perform the behavior again. Likewise, the more failure one experiences with a behavior the less likely he or she is to perform the behavior again. "Vicarious experience," or often called modeling, refers to social comparisons of oneself to others in regards to particular behaviors. If an individual sees another succeeding at a behavior, that individual's self-efficacy increases. Same is true for seeing others fail at a behavior. "Verbal persuasion" is the encouragement or discouragement one receives from social support systems. Finally, psychological factors also influence behaviors; for example, anger or embarrassment. While much research on health behaviors includes self-efficacy (Bandura, 2004; Holman & Lorig, 2004; Lorig, et al., 1999; Lorig, Mazonson, & Holman, 2005), the current research examined each component of self-efficacy in regards to self-management behaviors. Little research examines these components

independently of the others. Thus, based on the four constructs defined by Bandura (1994), the following research question is asked:

**RQ4: What components of self-efficacy are displayed in online health communities toward arthritis self-management, and do those components change over time?**

Looking now at these health behavior theories, the common component is self-efficacy, meaning that in order for behavior change to occur, self-efficacy must be present (Bandura, 1994). Theory of reasoned action predicts behavioral intention, considering also the influence of attitudes on behavior (Fishbein & Ajzen, 1975). In this theory, individual attitudes toward a health behavior consist of a belief that particular behavior leads to a certain outcome. This theory shares similarities with self-efficacy in that, if the health behavior is thought to be beneficial by the individual, he or she is more likely to perform the behavior. In fact, as a refinement of the theory of reasoned action, Ajzen (1985) proposed the theory of planned behavior which includes the component of self-efficacy. This theory posits health behaviors are governed not only by individual attitudes, but also by social environments and an individual's sense of control (Glanz, Rimer, & Lewis, 2002). These two theories have been applied to predict health behavior (Hardeman, Johnston, Johnston, et al., 2002), condom use (see Albarracin, Fishbein, Johnson, & Muellerleile, 2001), dieting success (Bagozzi, Moore, & Leone, 2004; Schifter & Ajzen, 1985), smoking cessation (Norman, Conner, & Bell, 1999), and preventative health behavior screenings (Brubaker & Wickersham, 1990; Fisher, Fisher, & Rye, 1995; Sheeran & Orbell, 2000) and others.

The health belief model was also proposed as a means to predict health behaviors based on attitudes and beliefs held by individuals (Rosenstock, 1974). This model's ability to predict an individual's health behavior is based on three core assumptions, including: (1) the feeling that a negative health condition (i.e., arthritis "flare") can be avoided; (2) the expectation that by taking a health-related action, he or she will avoid a negative health condition (i.e., by stretching daily, an arthritis patient hopes to remain limber); (3) the belief that an individual is capable of practicing the health behavior (i.e., individual feels confident and comfortable exercising). Rosenstock, Stretcher, and Becker (1988) added the component of self-efficacy in order to demonstrate an individual's ability to change negative health behaviors. The health belief model has been applied to a broad range of health behaviors, including preventative health behaviors (i.e., diet, exercise) and health-risk behaviors (i.e., smoking) as well as vaccination and contraception use (Glanz, Rimer, & Lewis, 2002). In a literature review of health belief model studies published between 1974-1984, Janz and Becker (1984) identified, across study designs and populations, perceived barriers as the most influential variable for predicting and explaining health-related behaviors.

Social cognitive theory proposes that behavior change is affected by environmental influences, personal factors, and attributes of the behavior itself (Bandura, 1989). The individual must possess self-efficacy. They must believe in their capability to perform the behavior and they must perceive that there is an incentive to do so. Self-efficacy is believed to be the most important characteristic that determines a person's behavioral change because the expected outcomes are filtered through a

person's expectations or perceptions of being able to perform the behavior in the first place (Bandura, 1994). The social cognitive theory has been applied to managing symptoms of HIV (Bandura, 1994b); risk behaviors (Schwarzer & Renner, 2000); physical activity (Booth, Owen, Bauman, et al., 2000); breast self-examination (Miller, Shoda, & Hurley, 1996); and oral health (Tedesco, Keffer, & Fleck-Kandeth, 1991).

Some similarities can be noted among these behavioral theories and models used to understand and enhance health behaviors. For example, many of the theoretical approaches highlight the role of an individual's perceived outcomes of behavior, although different terms are used for this component, including perceived benefits and barriers (health belief model) and outcome expectations (social cognitive theory and theory of planned behavior). Several of these approaches also emphasize the influence of perceptions of self-efficacy (health belief model, social cognitive theory) and perceived behavioral control (theory of planned behavior). Other theories and models feature the role of social influences, as in the concepts of observational learning (social cognitive theory) and perceived norm (theory of reasoned action and theory of planned behavior). Most of the theories and models, however, do not address the influence of the environment on health behavior. It is argued that individual's attitudes and social environments influence the practice of health behaviors (Fishbein & Ajzen, 1975). Based on the health behavior change theories, this research defined attitude as the perceived benefits or perceived barriers toward self-management behaviors. Based on the inclusion of attitude as a predictor of health behaviors in these health behavior change theories and models, the following was asked:

**RQ5: What are the perceived benefits of online health community members toward arthritis self-management?**

**RQ6: What are the perceived barriers of online health community members toward arthritis self-management?**

When applying these theories to chronic disease interventions, there are a wide range of outcome measures. Where self-efficacy is assessed, outcome measures tend to be specific to the chronic disease or to specific self-management strategies (Barlow et al., 2002; Bodenheimer et al., 2002; Lorig et al., 1999). For example, the Chronic Disease Self-Management Program (Lorig, et al., 1999) shows consistent improvements in patient knowledge, self-efficacy, and use of self-management strategies. An asthma self-management program called Wheezers Anonymous reported improvements in attack frequency, breathing difficulty, levels of depression, self-efficacy, and frequency of self-management behaviors (Barlow et al., 2002; Kotses, Stout, McConnaughy, et al., 1996). Diabetes self-management research (Bodenheimer, et al., 2002; Norris Nichols, Caspersen, et al., 2002) shows an increase in self-efficacy to practice self-management behaviors, specifically blood glucose monitoring. Across studies, research shows that as patient knowledge of chronic disease increases so does self-efficacy to perform self-management behaviors. Thus, it stands to reason that the engagement with the health information exchanged in online health communities can improve patients' knowledge, but also improve attitudes and feelings of self-efficacy related to chronic disease self-management. While the current research examined community members' engagement

in the online health community, other research questions are posed in relation to engagement:

**RQ7: Is there an association between engagement in online health communities and feelings of self-efficacy of self-management behaviors?**

Online communities have the potential to be an effective channel for improving health behaviors, including disease self-management, and subsequently, self-efficacy. However, little research examines the Internet to understand how computer-mediated communication influences attitudes and behaviors related to health. Online health communities are already being actively used by people with chronic disease (Kalichman, Benotsch, Weinhardt, et al., 2003), thus it stands to reason that community members are exchanging health information related to disease management. The content found within online health communities provides the opportunity to learn about chronic disease self-management from a patient's perspective.

Little research applies the multi-dimensional domains of health literacy to health communication. An introductory study (Willis, Wang, & Rogers, in press) used content analysis to identify domains of health literacy; however, little attention is paid to the improvement or development of health literacy over time within online health communities through use-generated health information or personal experience. Thus, this research examined community members' health literacy longitudinally to see how online health communities contribute to their understanding of their chronic disease diagnosis of arthritis.

**RQ8: How does health literacy appear to improve over the course of members' participation within online arthritis-related communities?**

## **CHAPTER III**

### **METHODS**

The purpose of this research was to examine the computer-mediated communication within online health communities to understand the role engagement plays in eHealth literacy and the perceived benefits, perceived barriers, and expressed feelings of self-efficacy toward self-management behaviors of people with arthritis. In order to answer the proposed research questions, this study used two methods: content analysis and concurrent ethnomethodology. First, a content analysis examined the self-management behaviors being discussed in the online health communities, but also community members' engagement in the community, and expressed attitudes and self-efficacy regarding self-management. Studies of computer-mediated online communities have generally used content analysis to understand members' communication (Han & Belcher, 2001; Finn, 1999; Rodgers & Chen, 2005). Content analysis is one of the most prominent research tools in mass media studies (Berelson, 1952) and is effective in analyzing content of media messages (Wimmer & Dominick, 1983). Concomitantly, ethnomethodology was used to obtain a holistic understanding of self-management behaviors "in action" within the online health communities. In order to attach context to the results of the content analysis, ethnomethodology was used to examine the exchanged computer-mediated communication of community members to understand how people with arthritis manage their disease and how self-management behaviors are used "off-line." As Rheingold (1993) suggested, these online encounters overlap



with members' physical worlds and their daily, lived experiences. It is simply not enough to quantify computer-mediated communication because without context, the results may not truly be applicable to patients. Ethnomethodological analysis was used to gather "thick description" of these online health communities to understand the cultural norms and codes (Geertz, 1973, p. 5). Since little research has been conducted in this area, a multi-method approach was most appropriate in order to provide an accurate description of self-management behaviors within online health communities related to arthritis. Table 1 outlines the research questions, variables, and the appropriate methods.

*Table 1.* Research questions and methods used to examine online arthritis community

RQ1: How are online health communities being used by patients with chronic disease to facilitate self-management behaviors through the exchange of computer-mediated communication?	Ethnomethodologic analysis
RQ2: What is the type of engagement of users within online health communities; and what, if any, is the relationship between engagement and the communities examined? <i>Variables: frequency of visits, total number of posts, average words per post, clarification, assessment, inference, strategies</i>	Content analysis (frequency, one-way analysis of variance)
RQ3: What arthritis self-management behaviors are discussed in online health communities; and what, if any, is the relationship between self-management behaviors and the communities examined? <i>Variables: information, drug management, symptom management, psychological consequences, lifestyle factors, social support, communication, other, perceived benefits, perceived barriers</i>	Content analysis (frequency, chi-square, one-way analysis of variance)
RQ4: What components of self-efficacy are displayed in online health communities toward arthritis self-management, and do those components change over time? <i>Variables: mastery experience, vicarious experience, verbal persuasion</i>	Content analysis (frequency, chi-square, one-way analysis of variance)
RQ5: What are the perceived benefits of online health community members toward arthritis self-management?	Content analysis (frequency, chi-square)
RQ6: What are the perceived barriers of online health community members toward arthritis self-management?	Content analysis (frequency, chi-square)

RQ7: Is there an association between engagement in online health communities and expressed feelings of self-efficacy toward self-management behaviors?	Content analysis (linear regression)
RQ8: How does health literacy improve over the course of members' participation within online arthritis-related communities?	Ethnomethodology analysis

Five online arthritis-related communities were identified through popular search engines, such as Google and Yahoo. These searches were meant to simulate patients' online searches for arthritis-related communities, revealing the most populated communities, using search terms like "arthritis community" or "arthritis support group," for example. The five communities that were identified are all dedicated to arthritis or other rheumatic conditions and have available history of previous discussion by community members. Four of these communities use bulletin boards to exchange information, organizing topics into threads. One is a "support group" within a social networking site, allowing only members to participate in online discussion. Due to the nature of archived information, this "support group" community was eliminated from the sample. Data could not be collected from the "support group" like the other online communities. The selected four online communities in this sample are sponsored or hosted by organizations with special interest in arthritis and include: About.com, Arthritis Foundation, Creaky Joints, and WebMD. All four of these online communities have peer-to-peer participation and do not include health care professionals or medical interventions. These four online communities were used for both content analysis and ethnomethodological analysis. Approval by the University's Institutional Review Board (IRB) was obtained for this research. Because this information is available in public domain, the proper names of the online health communities will be used, but the

quotations and content have been altered as to protect the privacy of the community members. This is in compliance with the University's IRB regulations for research of online communities.

## ***Content Analysis***

### ***Sampling***

This study used content analysis to examine the computer-mediated communication within online health communities. Constructed-week sampling has been shown to be a more efficient sampling method of online content than random sampling or consecutive day sampling, and two constructed weeks are needed for a time period of six months to ensure reliable estimates of online content (Hester & Dougall, 2007). Thus, four constructed-weeks of online computer-mediated communication from four online arthritis-related communities were sampled between January 1 and December 31, 2010. In total, 1,960 posts were read during the sampling period.

### ***Unit of analysis***

The unit of analysis refers to each post by individual community members. Here, post is defined as any narrative message authored by anyone within the online community and is related to arthritis self-management behaviors.

### ***Coders and Inter-coder Reliability***

Two graduate students served as coders. Coders participated in three two-hour training sessions and then, independently coded 10% of the sample. Inter-coder reliabilities were calculated at the beginning and the end of the study. Scott's pi (Scott, 1955) index was used to calculate inter-coder agreement, yielding an overall reliability of .95. The inter-coder reliabilities for each variable are reported below.

### ***Variables Measured***

This research examined self-management behaviors discussed within online health communities by people with arthritis, but also examined members' engagement in the community and expressed attitudes and self-efficacy regarding self-management behaviors. The following variables were examined with content analysis: self-management behaviors, engagement, perceived benefits, perceived barriers, and expressed feelings of self-efficacy toward self-management behaviors.

### Self-management

Because people with arthritis often have at least one other chronic disease to manage (CDC, 2009), self-management must be applicable to more than one chronic disease. Self-management approaches that focus primarily on medication and symptom management are disease specific, like Wheezers Anonymous (Barlow et al., 2002; Kotses, Stout, McConaughy, et al., 1996). However, for chronic diseases like arthritis, a more holistic approach is used with multi-components that improve disease knowledge and problem-solving skills. Approaches that use management of psychological consequences (e.g., depression), lifestyle (e.g., exercise), social support and communication are usually generic skills that can be used in a disease-specific context. Thus, for the purpose of the current research, Barlow et al.'s (2002) components of self-management were adapted and combined with Lorig et al.'s (1985) arthritis-specific self-management behaviors in order to fully examine computer-mediated communication of self-management behaviors by patients with other patients. The following were coded for evidence of the self-management behavior: 0 for absent, 1 for present. Scott's pi (1955) index was used, yielding .91 agreement.

*Information.* This refers to health information about a specific condition or treatment. For example, community members might seek information about arthritis following diagnosis by a health care professional or ask about a specific prescription medication.

*Drug management.* This refers to patients' understanding of their prescription medication(s) purpose, adherence to the prescribed treatment, and to experience with medication side effects. For example, community members may complain that a specific prescription medication causes dizziness or abdominal pains. This would be classified as medication side effects. Another example might be a discussion amongst community members as to how to remember to take their prescription medications on time. Additionally, any discussion regarding overcoming barriers to drug management would also be included here.

*Symptom management.* These are defined as techniques to deal with problems such as pain and fatigue. For example, a community member might be instructed by other members to engage in activities to distract from the pain of arthritis. Additionally, symptom management includes managing sleep and disease warning signs (e.g., flare), but also includes techniques as to how to be self-monitoring. For instance, a community member with a long history of chronic disease might share tips with other members about listening to one's body or "not overdoing it."

*Management of psychological consequences.* Although some formal self-management programs lump this category into "symptom management," it is important to examine the psychological consequences separately, especially in regards to self-

management behaviors. Physical symptoms and psychological consequences of disease are different in their effects on the patient (Holman & Lorig, 2004). Psychological consequences of disease include anger management, disease acceptance, dealing with depression or other emotions, and stress management. For example, a newly-diagnosed mother may come to the online community to vent feelings of anger and frustration over the diagnosis. Another example might be in regards to community members rallying around a member that is severely depressed over their loss of physical function.

*Lifestyle.* This includes exercise for maintaining and improving strength, flexibility, and endurance, especially the motivation to overcome barriers to exercise. For example, a community member may complain of arthritis “flares” following an exercise routine. This is a perceived barrier to engaging in exercise. Also included in lifestyle self-management behaviors are adherence to an exercise regime, discussion of nutrition or diet, and leisure activities. For instance, a community member may share with others that after dinner every night, she goes on a walk around the neighborhood with her dog.

*Social support.* Studies of online communities have often looked at social support (Rodgers & Chen, 2005; Wright, 2000), although not in relation to self-management behaviors. Social support here refers to family support or relationships with peers and friends found “off-line.” For example, a community member may complain that her husband does not believe she is in pain during a “flare.” Social support is influential in the performance of self-management behaviors (Gallant, 2003), and is often sought online (Cline & Haynes, 2001). However, this research will only

examine mention of social support in reference to the community member's "off-line" support network. This research assumes community members use the online health community for social support, and is interested how "off-line" social support self-management behaviors are facilitated within online health communities.

*Communication.* People with arthritis often have difficulty communicating effectively with health care professionals, family, and even friends. Here, communication refers to the strategies used or suggested by other members to communicate effectively "off-line." For example, a community member may suggest taking a list of questions or discussion points to a health care provider so as to make the most of the appointment time.

*Other.* Often, self-management entails more than researchers and health care providers realize. Thus, this category is defined to include decision-making, goal setting, problem-solving, managing uncertainty, or spirituality within the computer-mediated communication. For example, one community member may state that she is anxious about the progression of the disease. Other community members may provide strategies for coping with this uncertainty. This category was open coded, leaving opportunity to identify self-management behaviors common among people with arthritis that may not be included in formal self-management programs.

### Engagement

The engagement of community members within the online health community will be examined by drawing on Danaher et al.'s (2006) and Danaher & Seely's (2009) Web analytic categories. These categories are meant to show the physical engagement



of community members with the online community, including the frequency of visits, number of posts, and the average words per post. Additionally, as Perkin and Murphy (2006) argue the context within online communities encourage engagement with the information being exchanged by community members. These authors provide a framework for examining engagement in critical thinking online, using the categories of clarification, assessment, inference, and strategies. These categories will show how community members are engaging in the self-management information being exchanged within online health communities. Finally, in order to examine engagement, disease stage must be included as this might influence community members' use of the online health community. Below, operational definitions of each category are given. Using Scott's pi (1955) index, an intercoder reliability of .88 was achieved.

*Frequency of posts.* This category is designed to calculate how often individual community members post messages within the collected sample. For instance, within the sample, a community member may post more frequently after a new diagnosis or when being prescribed a new medication, but less frequent when chronic disease is stable. Here, the frequency in which community members post was tabulated.

*Number of posts.* This category is meant to tabulate the number of posts by individual community members within the collected sample to the online health community. A community member may only visit the online health community once per week but post multiple times during that single visit. Other the other hand, community members may visit the community daily and only post once.

*Average words per posts.* The number of words in each post will be coded in order to determine the average words per post by individual community members within the sample.

*Clarification.* This refers to “stating, clarifying, describing (but not explaining) or defining the issue” under discussion (Perkin & Murphy, 2006, p. 301). Here, clarification will be coded in relation to self-management behaviors. For example, a community member might describe their diet regime for other members, offering a personal account of a “lifestyle” self-management behavior. Another example might be a community member clarifying the appropriate way to inject medication subcutaneously.

*Assessment.* Assessment is to evaluate some aspect of the discussion, like making judgments on a situation, or providing evidence for an argument like links to external informational Web sites (Perkins & Murphy, 2006). For example, community members within online health communities may disagree on the most appropriate ways to exercise maybe based on personal experience or advice from health care professionals. In this discussion, a community member that posts an external link or medical article with information regarding exercising with arthritis is demonstrating assessment.

*Inference.* This is “showing connections among ideas; drawing appropriate conclusions by deduction or induction, generalizing, explaining (but not describing), and hypothesizing” (Perkins & Murphy, 2006, p. 301). For example, if a community member is experiencing a skin rash or irritable bowels, other members might infer that the prescription medications are causing these symptoms.

*Strategies.* This refers to the discussion or evaluation of possible actions (Perkins & Murphy, 2006) of self-management behaviors. For instance, if one community member is experiencing frustration stemming from a spouse's lack of empathy, other community members might rally around this member, proposing strategies to facilitate better communication. Another example might be the discussion and evaluation of prescription medications by community members.

*Disease stage.* This category is unique to the proposed research and is meant to identify the stage of disease or disease episode (e.g., flare) of the community member at the time of posting. For example, a community member may post more frequently during a flare or after a new diagnosis. Community members that do not have active disease symptoms may not engage as frequently within the online health community. This category was open-coded for, allowing the community members' language to be heard.

#### Perceived benefits

This refers to the beliefs about the effectiveness of arthritis self-management behaviors to reduce risk or seriousness of symptoms. This includes the explanation of how, where, and when to engage a self-management behavior, and what the potential positive result will be. For example, one community member may share with other members that she lost five pounds as a result of daily exercise. Content was coded as being present (1) or not present (0). The intercoder reliability was .90, using Scott's pi (1955) index.

#### Perceived barriers

This refers to the beliefs about the material and psychological costs of practicing self-management behaviors. For example, a community member might express lack of insurance as a barrier to adhering to a prescription drug treatment plan. Content was coded as being present (1) or absent (0). Here, the intercoder reliability was .93, calculated using Scott's pi (1955).

### Self-efficacy

Bandura (1994) includes four constructs in the conceptualization of self-efficacy: *mastery experience*, *vicarious experience*, *verbal persuasion*, and *psychological factors*. Each of these constructs was coded as being present (1) or absent (0). Using Scott's pi (1955) index, an intercoder reliability of .87 was reached. These constructs were operationalized as follows:

*Mastery experience.* Here, mastery experience refers to community members' personal experience with a self-management behavior. Typically, successful completion of a self-management behavior will increase self-efficacy, while failure tends to decrease the feeling of self-efficacy (Bandura, 1994). For example, a community member that participates in a doctor-prescribed diet plan may "fall off the wagon" during the holidays and share this experience with other community members.

*Vicarious experience.* This is operationalized here as the process of comparison between one community member and other community members. When a community member "sees" another member succeeding at a self-management behavior, their self-efficacy will increase; and where they "see" another member failing, their self-efficacy will decrease (Bandura, 1994). This process is most effective when an individual

perceives others as similar to themselves (Bandura, 1994). For instance, if a community member “sees” the failure of another member on a diet plan during the holidays, she may not engage in this self-management behavior because she, too, thinks she will fail.

*Verbal persuasion.* This refers to the encouragement or discouragement by community members to engage in a self-management behavior. For example, a community member may “verbally” persuade another member to seek marital counseling to learn effective communication strategies. Another example might be a community member’s “verbal” persuasion for another member to quit smoking.

Although content analysis quantifies and demonstrates associations among these variables, this method alone is not enough to understand how these variables exist “in action” within the online health communities. Ethnomethodology provides the context from which computer-mediated communication is exchanged. Observation of computer-mediated communication and members’ engagement in discussion show how people are using these self-management strategies within online health communities. Further, ethnomethodological analysis deconstructs the computer-mediated communication in order to understand the unique culture of people with arthritis within these online health communities. For instance, it is not enough to know that people with arthritis are exchanging information about exercise. It must be known in what capacity people with arthritis are discussing this self-management behavior. Thus, ethnomethodology was used to gain more insight into the computer-mediated communication of self-management behaviors by people with arthritis.

## Ethnomethodology

Ethnomethodology was introduced by Garfinkel (1967), an American sociologist. Ethnomethodology is a descriptive study of how individuals derive meaning from the world and communicate this understanding to cultivate social order (Garfinkel, 1967). Ethnomethodology treats meaning *contextually*, which means that relational patterns are analytically unpacked that enable sense to be made and understood (Lynch & Peyrot, 1992). “Context” for ethnomethodologists is not a fixed set of social, cultural, environmental, or cognitive factors. Instead, the term describes a “reflexively” composed relationship between actions and the “relevant specifications of identity, place, time, and meaning implicated by the intelligibility of those actions” (Lynch & Peyrot, 1992, p. 114). The primary aim of research in this discipline is to understand the methods and procedures that individuals apply to cultivate a sense of shared order (Taylor & Cameron, 1987). However, these methods and procedures are largely inadvertent and unconscious. Researchers, thus, need to glean these methods and procedures from the patterns that emerge in computer-mediated communication (Garfinkel, 1967).

Ethnomethodology is essentially a decoding operation (Apgar, 1983, p. 70). The ethnographer must examine, and essentially “learn,” the group’s language or discourse. The ethnographer must identify the key concepts and their associated linguistic labels (Emerson, 1983). Careful analysis of online computer-mediated communication can lead the ethnographer to an appropriately “thick description” of the online community (Geertz, 1983). Ethnographies have always taken advantage of written materials from a

culture (Denzin, 1997). Online communities present nothing but text. All behavior is verbal in the form of text. Ethnomethodological analysis is an attempt to recognize patterns, rules, or procedures that occur among online community members and the way in which these structures or conventions influence meaning and effect (Preece, 2005). Stories told in conversation are conventionally organized by the way tellers and recipients together contribute to the unfolding details of the narrative text (Denzin, 1997). Ethnomethodological analysis requires that the researcher “see” a complete conversation, which, in effect, may constitute a series of several exchanges. Silverman (1993) explains that the context of a particular message is actually found in the messages or statements that precede it. The ethnographer should become aware of the way in which language is used by online community members to exchange “coded” information, in which the meaning far transcends the mere words. For example, insights into the way in which an online community and its members see or define themselves can often be found in the root metaphors used in conversation (Denzin, 1997).

The computer-mediated discourse of five members from each of the four arthritis-related communities was analyzed, for a total of 20 members (N=6,578). Here, the five members were selected from the members contributing content found within the sampled content analysis. These five members were chosen based on the frequency of contribution to the online health community (Herring, 2004). The discourse from each member was analyzed from the original start date of contribution to and/or participation with the online health community through December 31, 2010. For example, one of the community members selected from the Arthritis Foundation joined

the online health community on November 5, 2005. All of this member's posts from November 5, 2006 through December 31, 2010 were read and analyzed (N=734). It was decided that this number was sufficient for understanding based on Strauss and Corbin's (1997) theoretical saturation. Purposive sample sizes are often determined on the basis of theoretical saturation or the point in data collection when new data no longer brings additional insights to the proposed research questions (Strauss & Corbin, 1997). Examining the computer-mediated discourse of these five community members helped to provide the context which is so important to ethnomethodology.

Studies of online communities have used an ethnographic approach (Baym, 2000; McLelland, 2002; Silver, 1999), message analysis (Preece, 2001; Braithwaite et al., 1999; Herring, 1996), group dynamics analysis (Korenman & Wyatt, 1996), and analysis of communication patterns (Quan-Haase, Wellman, Witte, & Hampton, 2002). Combining an ethnomethodological approach with a content analysis helps to develop a deep understanding of the communication and interactions within these four online health communities. Here, this research is concerned with the computer-mediated communication of self-management that translates into the "off-line" practice of these behaviors. Hine (2000) suggests that the spaces in which social interaction takes place on the Internet are "cultural artifacts" (p. 18). She contends that developing an understanding of the Internet space helps us to develop insights about how meaning is produced within the space. In the context of the online health communities, publicly available content allows for constant observation of computer-mediated communication – in the manner in which it was created. This dynamic interplay among



members is important to understanding how people with arthritis actually perceive self-management and use such health behaviors. Unlike content analysis, ethnomethodology is concerned with the cultural contextualization of the online health community, as the computer-mediated interaction provides opportunity to observe the representation of self-management behaviors.

## CHAPTER IV

### RESULTS

A total of 1,960 posts were collected during the sampling period (January 1 to December 31, 2010). The results showed that for the four-constructed week sample, there was a relationship in the number of cases analyzed and the websites sampled ( $\chi^2(3) = 2,200.87, p < .001$ ). Specifically, the results showed that the majority of cases came from the Arthritis Foundation (N=1,383, 70.56%), followed by About.com (N=248, 12.65%), WebMD (N=237, 12.09%), and Creaky Joints (N=92, 4.69%). Therefore, given that there were statistically significant results depending on the website sampled, the following results of the content analysis are reported across all four communities (in combination) and also uniquely for each individual community. For engagement, an overall variable was created by summing the responses (i.e., 0 – 4); likewise for self-management (i.e., 0 – 7), and self-efficacy (i.e., 0 – 3). The results for each research question are reported here, followed by a discussion.

To provide insight to the online health communities, the following is a brief illustration of demographic and health characteristics of the individuals sampled in the posts. Both males and females were found in the online communities, though in great disproportion. Females greatly outnumbered the males in all four communities (ratio 6:1). In three of the four online communities, there were posts that contained no report of gender. That was not the case in Creaky Joints; all of the sampled posts had mention of gender.

All four communities had members with various rheumatic disease diagnoses, although rheumatoid arthritis was most common (N=1,596, 81.4%). Ten percent of the sample had two rheumatic conditions, like rheumatoid arthritis and fibromyalgia. The remaining 8.6% of the posts included rheumatic conditions such as lupus, gout, and psoriatic arthritis. Similar across all four online health communities, members use fictional names and did not give specific geographic location. The members did share details of their arthritis, including diagnosis, medication(s), symptoms, and experience with the disease. Results are provided, next, for the previously outlined research questions.

**RQ1: How are online health communities being used by patients with chronic disease to facilitate self-management behaviors through the exchange of computer-mediated communication?**

The following are findings from the ethnomethodologic analysis of the four online health communities. Fifteen of the community members observed were female, five male. The members' ages ranged from 21 to 83 years. The majority of these members had rheumatoid arthritis, while two had osteoarthritis. Four members reported both rheumatoid arthritis and another chronic disease like lupus, fibromyalgia or Type 2 diabetes. Members' profiles are outlined in the Appendix. The following are patterns and contextual details observed among the online health communities. The “thick description” that follows seeks to unveil the interactions that people with arthritis engage in with like-others in the context of online communities in order to cultivate a sense of “sharedness.”

### ***Exchange of information***

Online health communities are being used by people with arthritis to seek information and share experience with others who have some type of rheumatic condition like arthritis. Seventy percent of the sampled posts (70%, N=1,372) contained content about self-management behaviors. In a few instances, caretakers posted within the online health community in search of answers. For example, a mother whose teenage son was recently diagnosed with arthritis joined the online health community for prescription drug information. She brought suggestions from the pediatric rheumatologist to the online health community for discussion amongst the community members.

My son's pediatric rheumatologist just prescribed [name of steroid] and [name of drug]. Does anyone have experience with these medications? I've had to take Prednisone before and don't like that my son would be taking a steroid at [age] 10. I'd appreciate any feedback you all might have for me. I just don't know the best way right now. (About.com)

The majority of community members, however, have a diagnosis of arthritis themselves. These members seek health information regarding arthritis and its symptoms, diagnosis, and prescription drugs, including side effects. The community is a trusted source of information for its members because of the common denominator of arthritis.

I don't think my doctor gets it. How do you explain your pain to your doctor? I try to tell him how bad I hurt, just all over. I don't know if he doesn't believe me, or he doesn't know what to do.. I don't know. Help me explain my pain. (Creaky Joints)

Some community members share experience as means to educate novice community members. Because arthritis affects patients differently, there is no one solution to every problem. Education then is meant to contribute to community members' knowledge of

the disease and its consequences as to improve problem-solving skills. Problem-solving skills are a key component of arthritis self-management programs because of the unpredictable symptoms of the disease. When a patient experiences a flare in symptoms, he or she must be able to assess the severity of the flare and address the symptoms. Living with a chronic disease requires a certain level of disease-specific health literacy if patients are to self-manage the disease and its symptoms.

Being exposed to other members' personal narratives of self-management provides other members with a variety of perceptions and strategies for practice of the behavior. For example, one community member posted within the online health community that she is experiencing a flare of symptoms and asked other members for suggestions to try to alleviate her pain. One community member posted that she has had a similar flare and used a heating pad and Tylenol to minimize the pain, thus suggesting these strategies to the ailing member. Another community member suggested a hot bath, and another an ointment. The personal narratives shared within the online community provide options from sources with the disease to quiet painful arthritis symptoms. Online members perceive other members that share a diagnosis as being credible, which is evident in the seeking of information. The ailing community member mentioned above posted the following, after her flaring symptoms subsided:

Thank you all for your suggestions. I ended up soaking my feet and ankles in Epsom salt. The pain and swelling went away eventually. Just had to wait it out. I'm hanging tough now. (WebMD)

Often, community members share experience and suggestions even when not asked to share. Computer-mediated communication comes in the form of personal experience in

these arthritis communities. Because it is assumed that everyone participating in the online health community has some form of arthritis, members communicate about experience related to arthritis. For example, it was common for community members to talk about morning stiffness. None of the posts described the parameters of morning stiffness, neither the feeling of morning stiffness or duration of morning stiffness. Yet, the posts that did mention morning stiffness all shared common strategies for overcoming this period of stiffness:

I set my alarm extra early for work. I have to give myself a few hours to loosen up, for the hot shower to start working. (CreakyJoints)

I go to water aerobics in the morning. I probably look pretty silly hobbling into the pool, but I feel great when I get out. The warm water really helps my morning stiffness. (Arthritis Foundation)

This shared understanding provided a foundation for which computer-mediated communication was exchanged about arthritis self-management behaviors. The self-management behaviors were understood amongst the members without explanation or rationale because all were practicing these behaviors in some fashion. In order to prevent self-induced flares, or flares as a result of “overdoing it,” members must know their bodies and how the disease responds to physical behavior(s). Sometimes, however, a flare in symptoms happens spontaneously, not as a result of individual behavior, but just as an affect of the disease. The arthritis symptoms, including pain and disability, were shared among members of the online health communities, and all had knowledge and/or experience in dealing with such flares in symptoms. This knowledge and/or experience of self-management behaviors were the basis for participation in the online health community.

### ***Engagement related to disease symptoms***

As mentioned previously, five community members from each online health community were selected for further examination longitudinally of their engagement in the computer-mediated communication. Ethnomethodological analysis revealed a pattern of engagement in the online health communities. Community members engaged in the online community more when newly diagnosed or during flaring symptoms. These particular disease stages make necessary the need for information or shared experience from other community members. For instance, a newly diagnosed community member wants information quickly so as to make informed health decisions:

My rheumy [rheumatologist] gave me information to read on the different medications he thinks I should consider taking [for my arthritis]. There are just a lot of scary side effects. What medications do you all take and what has been your experience with side effects? I need help making this decision. (About.com)

The online health communities overcome physical barriers, including time and distance. Members are able to engage in the online health community, often with instant information from members across the country, and in some cases, the world. Because of this ability, online health communities provide information from different perspectives instantaneously to aid in the self-management of arthritis symptoms. A community member experiencing a flare of symptoms wants strategies that other community members have used to reduce disease affect:

I have been stuck on my couch for days. My knees and ankles hurt too much to do anything. I have asked my doctor for some pain medication, but I haven't felt like going to the pharmacy to pick it up. I definitely need a pick-me-up. Any ideas? (Arthritis Foundation)

Arthritis is debilitating and often, limits mobility. Lifestyle behaviors are dictated by arthritis symptoms. Community members that experience remission disappear from the online health community for extended periods of time. Others notice and post content urging the community member to “check in” with the community. One community member wrote:

I guess we just post when we’re hurting. Once we feel better, we’re out doing things we can’t now. Living! [Name of member], I hope you are enjoying yourself. Check in when you can. We miss you. (WebMD)

Of the 20 community members observed, none disappeared altogether from the online health community. However, one member took a leave of absence for six months (between March and August 2009). His explanation to the online health community follows:

I'm so sorry, friends! I didn't realize I have been gone for so long. I hope you all missed me! I have been out living. My new medicine is doing the trick. I feel so alive. My son took me hiking in the Grand Canyon. We didn't go far, but we went! I'm back now. Update me. How's everyone feeling? (Arthritis Foundation)

The other members were quick to understand, all posting memories of what it was like to be “normal” before the disease diagnosis.

These online health communities were also used as a means of social support, which is another key component of arthritis self-management programs. A cyclical pattern was seen across the four health communities: a new member joins the online health community, asks the other members questions regarding the disease diagnosis, posts experiences related to the new diagnosis, including emotions and feelings, medications, social networks, and rheumatologists. As the new member becomes



familiar with the disease, he or she no longer posts as a “novice,” but as an “expert” patient, giving advice and personal experience to others that have recently joined the online health community.

### ***Acceptance of disease***

The exchanged computer-mediated communication within the online health communities are narratives, composed by people with a shared diagnosis – arthritis. People with chronic disease have to manage their disease and its affect on their lives, and often this includes identity management. Within the online health communities, many members complained that “no one understands what it's like to have this monster [arthritis]” (About.com). Generally, arthritis cannot be seen and this was found to conflict with members’ desires to be understood and empathized with in the “off-line” world. The phrase “You don’t look sick...” was common in all four communities. In some cases, members complained of insensitivity by their rheumatologists or general practitioners. For example, the following post is from WebMD:

I'm so tired of feeling inadequate. My rheumatologist does not have any respect for me or even any empathy for my situation. He is in and out, not even giving me five minutes. I have so many questions that I want answers to.

Physicians were not spending enough time with the community members in order to answer questions adequately or address their concerns. Spouses and family members were often mentioned as “not caring” or “does not understand.” For instance, community members discussed having to cancel plans with friends, often without any notice due to an arthritic flare. Members felt as if their friends thought arthritis was being given as an excuse, or that they didn’t understand the pain associated with the

disease. Mothers with arthritis posted feelings of being overwhelmed. Many newly diagnosed mothers feared they would fail at being a mother because they are no longer able to do what they did before the diagnosis.

I can't do anything anymore. I look at my 18-month year old baby and wonder how I'll ever manage to do it all. He deserves the very best. I don't know if I can do it. (Arthritis Foundation)

Maintaining semblance of a “normal” life was important to newly diagnosed members.

Most wanted to continue with their activities and responsibilities, though most encountered obstacles due to the disease. For instance, one community member talked about being unable to play soccer with her son anymore. She felt fatigued most days and no longer participated in her son’s hobbies. Community members also used the online health community to “vent” feelings related to arthritis and the impact the disease has on their lives. For example, one community member wrote the following (Creaky Joints):

I hate this disease. I am in constant pain. I walk funny. I hurt all the time. My boss thinks I’m weak. I ask for too many days off. I feel tired most days. I take steroids to help me make it through the day. I just don’t see anything better. I know you guys understand. I just hate the world today. I needed to vent. My arthritis sucks today.

Often, community members come to be comforted by other members. They know the online health community has others that can relate to the disease diagnosis, symptoms, and even prognosis. This outlet provides like-individuals to communicate like-feelings about a chronic disease experience. Often, community members console other members and repeatedly check in with them to ensure improvements in spirit:

[Name of member], I was thinking about you today. You have been in my prayers recently. I know the pain you are in and it's not easy. You can do it, though. We're all rooting for you! Let us know how you are doing.  
(Arthritis Foundation)

Members within the online health communities know that other members will have experienced something similar and can relate to their situation. This feeling of similarity created a sense of "sharedness" among the community members.

### ***Patients define self-management***

Some of the sampled posts (25.7%, N=504) showed co-morbid conditions. Prescription medication plans and self-management strategies become complex when dealing with more than one chronic disease. For example, community members with diagnosis of both rheumatoid arthritis and Type II diabetes must be knowledgeable about both conditions, including symptoms, prescription medication plans, and how one disease affects the other. One community member posted about her flaring arthritis symptoms which limited her ability to cook dinner for herself. Even though her Type II diabetes requires her to stay away from fast food, she chose fast food for dinner three nights out of the week because of her flaring arthritis. This particular community member posted that she knew better than to choose fast food but did not feel as if she had any other option because her arthritis was limiting her mobility and causing her to be fatigued. Community members with co-morbid diagnoses discussed arthritis as their main ailment with the other chronic

conditions as subsequent diagnosis. For example, a community member from WebMD posted the following:

I try to listen to what my body's telling me. Sometimes it is hard to tell if it's the RA [rheumatoid arthritis] or if it's something else. I have to keep my medications straight because I have heart disease and sometimes my body doesn't like the pills I take. Or, that's what I think. My rheumy says they're not related, but I know my body. Something is just not right. Anyone else feel weird after taking their pills?

Being attentive to one's own disease symptoms and affect is part of chronic disease self-management. However, the application of this knowledge to make appropriate self-management decisions is rooted in health literacy which will be discussed later.

The quality of a patient's life is influenced by his or her practice of self-management behaviors in order to reduce the disease affect. Members often know the "right" thing to do (e.g., adhere to a physician's instructions), but because they are experiencing arthritis symptoms, choose another path they themselves deem most appropriate for the current situation. Across the four online health communities, members used previous disease experience to guide their current behavior, but also to predict possible future outcomes. For instance, the following is a post from About.com:

My rheumy wants me to exercise more, thinks it will help my knees feel better. Not sure how, though. I used to belong to Anytime Fitness, went three times a week – even worked with a personal trainer. I stopped, though, at the end of last year. Just felt like [the exercise] made everything worse. I mean, I starting having serious flares, missed a lot of work. I don't really think exercise is the answer for me. My body just doesn't approve. Does anyone have a workout routine that doesn't hurt more than it helps? I don't want a repeat of last time.

This post demonstrates perceived barriers to participating in exercise, based on the community member's previous experience with exercise. However, this member does inquire as to how other members exercise, showing an interest in following her "rheumy's" orders, but on her own terms.

Defining a self-management behavior, like exercise, is personal and requires trial and error, often being influenced by other members' success/failures with the behavior. More than that, definitions or uses of self-management behaviors change as the disease changes, or are response to current disease symptoms. For example, many community members had experience with taking steroids to control the symptoms of arthritis. For newly diagnosed patients, steroids were described as the "miracle drug," or as being a "lifesaver." The length of diagnosis changed the perception of the steroids, however. Steroids are known to have side effects like weight gain or thinning of the bones (van Everdingen, Jacobs, Siewertsz van Reesema, & Bijlsma, 2002). Based on personal experience with side effects, the following was posted in the WebMD community:

[Name of steroid] is like the tree of good and evil. Looks and feels so good but in the end, bites you in the ass. I've gained some serious weight on [name of steroid], but can't seem to kick the habit. I tried to wean myself off, but just ended up in a flare and had to do a burst [large dosage of steroid] and now am on 25 mg [name of steroid].

### ***The making of an "expert" patient***

Longitudinal analysis of the online health communities showed similar a pattern across the four arthritis-related communities: Members join the online

health communities in search of health information but remain active members and continue to share their disease experience with others searching for information long after the disease diagnosis. An act of transformation happens within these communities: members move from information seekers to disease experts. An “off-line” experience (e.g., new diagnosis) causes the individual to seek information online, including from these online health communities. The individual asks questions of the other members and engages in the topics of computer-mediated communication. The day-to-day experience of living with arthritis is enough to influence an individual’s engagement with the online health community. This disease experience becomes part of the larger disease narrative that is present within these online health communities related to arthritis. Soon, individuals become part of the larger disease narrative and use their experience to help new members to the community. This cyclical process is reflective of an individual’s health literacy related to arthritis self-management. For example, a newly diagnosed patient might seek out specialized health information from the online community. This need for information is what first brings the patient to the online arthritis community. Other community members’ shared experience and knowledge present within the online community combined with the individual’s own experience with the disease and other “off-line” factors (e.g., social support, rheumatologist, Web information) work together to inform the individual’s health literacy, or understanding of the disease. Due to the abilities of the Internet and availability of archived

information, community members have access to previous computer-mediated communication exchanged within the community. Thus, health literacy is not restricted to understanding the present stage of the disease. Community members have the advantage of reading previous content and relating other members' experience to their ever-changing health situation. In fact, it was common for community members to refer new members to previous threads of communication. Some threads of computer-mediated communication were created for the purpose of educating new members on the disease and its symptoms. This *desire of information* (whether seeking, exchanging, or both) acts as the foundation in which the online health communities are built.

**RQ2: What is the type of engagement of users within online health communities; and what, if any, is the relationship between engagement and the communities examined?**

Engagement within these online health communities was identified using the following variables: *frequency of visits*, *total number of posts*, and the *average number of words per post*. The intercoder reliability was calculated using the Scott's pi (Scott, 1955) index and yielded .90. Across the four online communities related to arthritis, members averaged more than three visits per week ( $M= 3.4125$ ,  $SD=2.2243$ ), and averaged the following number of visits per community: 3 ( $SD=2.0167$ ) visits About.com, 6 ( $SD=4.1112$ ) visits Arthritis Foundation, 0.65 ( $SD=.9124$ ) visits Creaky Joints, and 4 ( $SD=3.0027$ ) visits WebMD. However, these visits did not always result in participation. A community member may log into the health community but may only choose to

observe or “lurk” over the computer-mediated communication. Community members averaged 107 ( $SD=64.38$ ) posts last year, resulting in almost two posts ( $M=1.7$ ,  $SD=1.0013$ ) per week. The average posts per week varied by community: 1 ( $SD=.8432$ ) post About.com, 4 ( $SD=2.341$ ) posts Arthritis Foundation, 0.4 ( $SD=.0667$ ) posts Creaky Joints, and 1.4 ( $SD=.9871$ ) posts WebMD. The average total post collected from across these four arthritis communities contains 57 ( $SD=23.7679$ ) words.

Additionally, this research also identified how community members engage in eHealth literacy, or critical thinking, drawing on Perkin and Murphy’s (2006) categories: *clarification*, *assessment*, *inference*, and *strategies*. Assuming that eHealth literacy requires all four of these categories, content was coded here on the word level. So then, a post might contain more than one of these categories. Across all four online communities, *clarification* was most frequently identified with 42.2% of posts ( $N=828$ ); *assessment* was found in 28% of posts ( $N=548$ ); 10% of the posts ( $N=199$ ) contained statements of *inference*; *strategies* were found in 29.8% of the posts ( $N=584$ ). The following are frequencies of the critical thinking categories for each online health community. For About.com, *assessment* was found in 36.3% of the posts ( $N=90$ ), 32.3% of the posts ( $N=80$ ) contained statements of *clarification*, *strategies* were found in 25.4% of posts ( $N=63$ ), and *inference* found in 12.1% of posts ( $N=30$ ). In the Arthritis Foundation community, *clarification* was found most frequently (30.9%,  $N=528$ ), followed by *strategies* (21.2%,  $N=362$ ), *assessment* (14.4%,  $N=247$ ), and *inference* (4.2%,  $N=362$ ). For Creaky Joints, *strategies* were found most often (48.4%,  $N=44$ ), followed by *clarification* and *assessment* (both 41.8%,  $N=38$ ), and *inference* (4.4%,  $N=4$ ). Finally, Web



MD, contained evidence of *clarification* (76.3%, N=180), followed closely by *assessment* (73.3%, N=173), *strategies* (48.3%, N=114), and statements of *inference* (39.4%, N=93).

In order to identify the differences among the four different online health communities in terms of engagement, a composite continuous score was entered as a dependent variable in a one-way analysis of variance (*ANOVA*). See Tables 2 and 3. Results showed that the four communities were significantly different from one another in terms of engagement ( $F(3, 1956) = 184.52, p < .001, \eta^2_p = .22$ ). Results showed that engagement was highest in the WebMD community ( $M = 2.37, SD = 1.25$ ), followed by Creaky Joints ( $M = 1.36, SD = .91$ ), About.com ( $M = 1.06, SD = .91$ ), and the Arthritis Foundation community ( $M = .88, SD = .83$ ). The Bonferroni correction was used for pairwise comparison among all of these communities and was significant ( $p < .05$ ). See Figure 1.

This research also looked for statements related to disease stage; for example, active symptoms, flare, being newly diagnosed, or no report of disease stage. This information was open-coded, so as to capture patients' language in reference to their disease. Partly, the purpose of ethnomethodological research is to understand the characteristics of a specific group or culture (Taylor & Cameron, 1987), but also the language that creates shared meaning for a group or culture (Emerson, 1983). Thus, it was important to collect members' own description of the disease and its symptoms. Across the four online health communities, 28.3% of the sampled posts ( $N=555$ ) contained obvious mention of active disease symptoms. Mention of disease symptoms

were most often conjoined with affected joints. The following posts illustrate this discussion of disease symptoms:

My knees are hurting today. I don't know if it's because of the weather – we're getting a lot of rain here, well and have been the past three days. (Arthritis Foundation)

Boy, my wrists just don't want to work today. (WebMD)

My ankles have been swollen all day. I tried rotating ice and then a heating pad – neither worked. So, I'm lying on the couch. Not much else I can do until the pain goes away. (Creaky Joints)

The other disease stages were not mentioned as frequently: 4.3% flare ( $N=85$ ), 2.3% remission ( $N=45$ ), 2.1% newly diagnosed ( $N=41$ ); 1% severe symptoms ( $N=1$ ). Almost 63% did not obviously mention disease stage and were coded as no report.

**RQ3: What arthritis self-management behaviors are discussed in online health communities; and what, if any is the relationship between these self-management behaviors and the communities examined?**

The following are frequencies of reported self-management behaviors found in the sample, across the four arthritis communities ( $N=1,960$ ): 27.8% posts with information ( $N=545$ ), 29.3% posts with drug management ( $N=575$ ), 22.7% posts with symptom management ( $N=444$ ), 6.9% posts with psychological consequences ( $N=136$ ), 9.3% posts with lifestyle factors ( $N=183$ ), 26.6% posts with social support ( $N=522$ ), and 16.7% posts with communication ( $N=327$ ). Also included in the coding variables for self-report of self-management behaviors was *other*. This category was open coded in order to capture self-management behaviors and topics that are discussed amongst community members that are not included in formal self-management programs

(Barlow et al., 2002; Lorig et al., 1985). Repetitive topics included discussion of joint replacements, insurance and prescription drug coverage (i.e., Medicare options), physical therapy, benefits of drinking tea, diet, smoking cessation, blood work (i.e., rheumatoid factor), and alcohol. These topics will be discussed in detail later.

The following are results for each individual community's computer-mediated communication of self-management behaviors: About.com showed *drug management* (27.8%, N=69) as the most frequent topic, followed by *information* (25.8%, N=64), *symptom management* (23.4%, N=58), *social support* (20.6%, N=51), *lifestyle factors* (15.7%, N=39), *communication* (10.1%, N=25), and *psychological consequences* (9.7%, N=24); Arthritis Foundation reported *social support* most frequently (27.5%, N=471), *drug management* (19.6%, N=335), *information* (19.4%, N=332), *communication* (17.7%, N=302), *symptom management* (12.2%, N=209), *lifestyle factors* (8.4%, N=143), and *psychological support* (2.8%, N=48); Creaky Joints showed *drug management* (45.1%, N=41) as the most frequent topic, followed by *symptom management* (31.9%, N=29), *social support* (30.8%, N=28), *information* (27.5%, N=25), *communication* (24.2%, N=22), *lifestyle factors* (16.5%, N=15), and *psychological factors* (13.2%, N=12); and finally, WebMD reported *symptom management* most frequently (61.9%, N=146), *drug management* (54.2%, N=128), *information* (52.1%, N=123), *social support* (52.1%, N=123), *psychological factors* (22%, N=52), and *lifestyle factors* (22%, N=52).

The data was also examined for differences among the four health communities in terms of self-reported self-management behaviors. Before getting into specific details about each of the self-management behaviors and how they compared in terms of posts

in the four health communities, a composite score was calculated to represent self-management behavior as a whole (see Tables 4 and 5). Overall self-management was entered as a dependent variable into a one-way analysis of variance (ANOVA). Results, illustrated in Figure 2, showed that the four communities were significantly different from one another in terms of reported self-management ( $F(3, 1956) = 233.191, p < .001, \eta^2_p = .19$ ). Results showed that self-reported self-management behaviors were highest in the WebMD community ( $M = 2.94, SD = 1.65$ ), followed by Creaky Joints ( $M = 1.88, SD = 1.51$ ), About.com ( $M = 1.33, SD = 1.22$ ), and the Arthritis Foundation community ( $M = 1.11, SD = 1.13$ ). Pair wise comparison showed that the differences among all of the communities were significant ( $p < .05$ ), except for the differences between About.com and the Arthritis Foundation, where the differences approached significance ( $p = .056$ ).

With regards to information as a self-management behavior, results showed that the four communities were significantly different from one another ( $\chi^2(3) = 81.41, p < .001$ ). See Figure 3. When looking at the four different communities, we can see that About.com, the Arthritis Foundation, and Creaky Joints had approximately a quarter of the cases coded as information self-management behavior (25.80%, 24.01%, 27.17%, respectively). However, nearly twice as many posts on WebMD (52.32%) were coded as information.

With regards to drug management as a self-management behavior, results showed that the four different communities were significantly different from one another ( $\chi^2(3) = 99.51, p < .001$ ). See Figure 4. When looking at the four different

communities, we can see that about a quarter of the posts on About.com (27.82%) and the Arthritis Foundation (24.30%) were coded as drug management. There were more posts that were coded as drug management on Creaky Joints (44.57%) and WebMD (54.43%).

With regards to symptom management as a self-management behavior, results showed that the different communities were significantly different from one another ( $\chi^2 (3) = 257.92, p < .001$ ). See Figure 5. When looking at the four different communities, the WebMD had the highest percentage of cases coded as symptom management (62.03%), followed by Creaky Joints (31.52%), About.com (23.39%), and the Arthritis Foundation (15.18%).

With regards to psychological consequences as a self-management behavior, results showed that the four different communities were significantly different from one another ( $\chi^2 (3) = 116.56, p < .001$ ). See Figure 6. Results indicated that the highest percentage of posts addressing psychological consequences was below 22%. WebMD had the highest percentage of these posts (21.94%), followed by Creaky Joints (13.04%), About.com (9.68%), and the Arthritis Foundation (3.47%).

With regards to lifestyle as a self-management behavior, results showed that the four different communities were significantly different from one another ( $\chi^2 (3) = 84.924, p < .001$ ). See Figure 7. Similar to addressing psychological consequences as a self-management behavior, the highest percentage of posts addressing lifestyle as a self-management behavior was below 22%. WebMD had the highest percentage of

these posts (21.94%), followed by Creaky Joints (16.30%), About.com (15.73%), and the Arthritis Foundation (5.57%).

With regards to social support as a self-management behavior, results showed that the four different communities were significantly different from one another ( $\chi^2 (3) = 92.233, p < .001$ ). See Figure 8. Results illustrated that more than half of the posts on WebMD (51.90%), a third of posts on Creaky Joints (31.52%), nearly a quarter of the posts on the Arthritis Foundation (23.07%), and about one-fifths of the posts on About.com (20.56%) were coded as social support as a self-management behavior.

Finally, with regards to communication as a self-management behavior, results showed that the four different communities were significantly different from one another ( $\chi^2 (3) = 39.608, p < .001$ ). See Figure 9. Results illustrated that about a third of the posts on WebMD (29.11%), less than a quarter of posts on Creaky Joints (23.91%), 15.25% of the posts on the Arthritis Foundation, and about one-tenth of the posts on About.com (10.08%) were coded as communication as a self-management behavior.

To summarize, Figure 10 illustrates the percentage of cases coded on the different categories of self-management behavior. Results indicated that drug management and information were the highest self-management behaviors expressed in the About.com posts, followed by symptom management, and social support. A similar trend was observed with posts within the Arthritis Foundation community, where the highest percentage of posts were coded as information, drug management, and social support. Drug management had the highest percentage of cases for Creaky Joints' posts, followed by symptom management, social support, and information.

Finally, symptom management had the highest percentage of cases within posts on WebMD, followed by drug management, information, and social support.

**RQ4: What components of self-efficacy are displayed in online health communities toward arthritis self-management, and do those components change over time?**

Content was coded for the following categories of self-efficacy related to self-management behaviors: *mastery experience*, *vicarious experience*, *verbal persuasion*.

*Mastery experience* was found to be present most frequently (49.5%;  $N=971$ ), followed by verbal persuasion (28.2%;  $N=553$ ) and vicarious experience (21.3%;  $N=417$ ).

A composite score of the three categories of self-efficacy was created. Overall self-efficacy was entered as a dependent variable into a one-way analysis of variance (ANOVA). Results, illustrated in Figure 11, showed that the four communities were significantly different from one another in terms of self-efficacy ( $F(3, 1956) = 43.144$ ,  $p < .001$ ,  $\eta^2_p = .06$ ). See Tables 6 and 7. Results showed that self-efficacy was highest in the WebMD community ( $M = 1.57$ ,  $SD = .94$ ), followed by Creaky Joints ( $M = 1.26$ ,  $SD = .92$ ), the Arthritis Foundation ( $M = .91$ ,  $SD = .90$ ), and About.com ( $M = .81$ ,  $SD = .78$ ). The Bonferroni correction was used for pair-wise comparison among all of these communities and was significant ( $p < .05$ ), except for those between About.com and the Arthritis Foundation (*ns*).

With regard to mastery experience, results showed that the four communities were significantly different from one another ( $\chi^2(3) = 115.89$ ,  $p < .001$ ). When looking at the four different communities, we can see that WebMD has the majority of cases

coded (79.90%), followed by Creaky Joints (64.13%), Arthritis Foundation (46.05%), and About.com (35.49%).

With regard to vicarious experience, results showed that the four communities were significantly different from one another ( $\chi^2 (3) = 52.21, p < .001$ ). When looking at the four different communities, WebMD has the most coded cases (37.97%), followed by Creaky Joints (26.09%), About.com (21.77%), and Arthritis Foundation (18.00%).

With regard to verbal persuasion, results showed that the four communities were significantly different from one another ( $\chi^2 (3) = 24.30, p < .001$ ). When looking at the four different communities, WebMD has the most coded cases (40.08%), followed by Creaky Joints (35.87%), Arthritis Foundation (26.54%), and About.com (23.39%). See Figure 13 for the percentage of cases coded self-efficacy within each health community.

The expressed self-efficacy toward self-management behaviors by five members from each online community was also examined longitudinally. It was found that the expressed self-efficacy of arthritis self-management improved with practice of the behavior. For instance, a community member decided to start water aerobics because of suggestions from other members. However, participating in water aerobics initiated a flare in her arthritis symptoms. Her feelings of self-efficacy toward exercise were then negative because of this experience. After encouragement (or *verbal persuasion*) from other community members, she decided to try water aerobics again. The second experience was positive for this community member which increased her feelings of self-efficacy toward exercise. Four months later, this same community member was



found encouraging a new member to exercise and even suggested water aerobics as a possible option:

Water aerobics has been so great for my joints. I've even lost weight! I go about three times each week – usually to the early class. After work I'm too tired to even think about getting in the pool so mornings work best for me. I just love it. The water feels good and [after the water aerobics class] I sit in the hot tub for a few minutes. [This] does wonders for my day. (Arthritis Foundation)

Newly diagnosed community members come to the online health community looking for specific information. Since the diagnosis is recent, these members tend to have low self-efficacy. As the disease progresses and the community members learn more about its symptoms, the better self-management he or she practices. With time and practice, community members figure out what is successful in managing symptoms. Thus, their self-efficacy improves as they learn successful strategies to managing arthritis. These community members then share successful self-management strategies with the other members.

However, patterns between expressed self-efficacy and disease stage were also found among the five active community members. Members who were experiencing a flare in symptoms often expressed less self-efficacy in regards to self-management behaviors. One community member posted the following:

I can't do anything. My hands are hurting so much. I can't open my pill bottle. I've tried too hard and now my hands hurt from doing that. I can't cook. I don't really feel like eating anyway. I can't type. I'm using my [voice recognition software]. I haven't been to work in a few days. I feel so hopeless. I hate when I feel like this. (About.com)

This same member posted this three days later:

My rheumy gave me a burst of [name of steroid] and I feel great! My hands are working again. I talked to my pharmacy about easy-to-open pill bottles. I think that'll help me a lot when my hands don't work.  
(About.com)

When arthritis symptoms are controlled, community members expressed self-efficacy toward self-management behaviors. In many cases, community members verbally persuaded other members to try self-management.

**RQ5: What are the perceived benefits of online health community members toward arthritis self-management?**

**RQ6: What are the perceived barriers of online health community members toward arthritis self-management?**

This research examined the perception of community members regarding self-management behaviors. This research coded content with perceived benefits and perceived barriers related only to self-management behaviors. Across the four online communities, more posts contained evidence of perceived benefits ( $N=851$ ) than perceived barriers ( $N=530$ ). Results showed that the four communities were significantly different in terms of perceived benefits expressed in the posts regarding self-management behavior ( $\chi^2 (3) = 89.594, p < .001$ ). The highest percentage of cases coded as benefits was in the WebMD posts (68.78%), followed by Creaky Joints (57.61%), Arthritis Foundation (40.27%), and About.com (31.45%). Results also showed that the four communities were significantly different in terms of posting about perceived barriers ( $\chi^2 (3) = 66.885, p < .001$ ). The highest percentage of cases coded as benefits was in the WebMD posts (48.52%), followed by Creaky Joints (30.43%), Arthritis Foundation (24.22%), and About.com (20.97%). As illustrated in Figure 12, participants

of the four communities generally expressed more benefits than barriers to practicing self-management.

**RQ7: Is there an association between engagement in online health communities and expressed feelings of self-efficacy toward self-management behaviors?**

Linear regression was used to determine the extent to which a relationship exists between engagement in the online health community and expressed self-efficacy of self-management behaviors. There was found to be a correlation between engagement and self-efficacy of self-management behaviors. The relationship between engagement and feelings of self-efficacy is positive,  $R^2 = .40$ ,  $F(1, 1958) = 1291.40$ ,  $p < .001$ .

**RQ8: How does health literacy appear to improve over the course of members' participation within online arthritis-related communities?**

Examining five members' posts from each online arthritis community longitudinally to assess their health literacy revealed three patterns. First, community members initially join the online health community in search of information. As community members continue to engage with the community, sharing experiences related to arthritis in real time with other members, their knowledge of the disease and its affect improved. Real time allows urgent questions to be answered immediately from any of the community members, eliminating barriers such as geographic location, demographic, or disease stage. So then, during a flare, a community member might rely on the online health community for strategies to decrease the symptoms. Having access to others' suggestions gives the suffering member options in managing his or her flare.

Many evidence-based self-management programs include problem-solving as a skill necessary for managing chronic disease (Holman & Lorig, 2004). For an unpredictable disease like arthritis, problem-solving skills come from experience living with the disease. The online health community and its characteristics, like archived computer-mediated communication, provide instant, in-depth information, also including evaluation, regarding self-management behaviors.

Similarly, patients with arthritis must be aware of the consequences of their own actions. Extended physical exertion tends to aggravate the symptoms of arthritis, including pain, stiffness, and fatigue. When a community member's prescription medications are successful in controlling arthritis symptoms, the community member tends to be more active. For example, one member in the Arthritis Foundation community termed this the "feel good syndrome." This 82-year-old male warns other members not to let this "good feeling fool you," but that "doing too much on your feel-good-days will put you on the couch come tomorrow." This anecdote shows that persons with arthritis must know their own physical limitations. "Overdoing it" can overwork the body and cause disease symptoms to flare. Thus, community members must actively monitor their disease and the affect that certain behaviors have on their symptoms. For instance, knowing the point of "overdoing it" based on previous experience or the experience of others prohibits the aggravation of symptoms.

Second, most community members that have long histories of living with arthritis have improved knowledge of prescription drugs. As seen across the four online arthritis communities, newly diagnosed patients often have to try several drug

combinations before a successful combination is found. Or, in some instances, prescription medications stop controlling the symptoms and new medications are prescribed. For instance, the following community member posts her prescription medication history in her signature: “Tried MTX [Methotrexate] and Plaquenil for 5 years, Humira then Enbrel, now Remicade.” Within two of the four online arthritis communities, new members were directed to archived content about the different prescription medications offered for arthritis. Community members seeking information on prescription medications were often told about biologic medications, the most recent pharmaceuticals approved by the Food and Drug Administration for arthritis. Strategies as to how to administer these types of medications were common, including the preferred time of day, food intake, or how to inject medications subcutaneously. Computer-mediated communication was also exchanged about steroids and other pain killers. Steroids are a common medication prescribed to people with arthritis, especially if the arthritis symptoms are extremely active. For example, Prednisone is a steroid that quickly works to relieve pain, stiffness, and swelling in the joints. This was often suggested to new members as being a “miracle” medication. Members’ knowledge of prescription medications was also accompanied by experience with medication side effects. For example, many members shared the experience of nausea and dizziness with a particular biologic medication, Methotrexate. Some shared strategies for administering the medication to avoid such side effects, including injecting the medication subcutaneously instead of taking orally. Taking Methotrexate by injection requires that patients accurately measure the dosage and be able to administer

subcutaneously. Skills like these are commonly discussed within the online health communities.

The final pattern seen in these online health communities is the uncertainty related to the diagnosis and progression of the disease. To expand on this notion, people diagnosed with arthritis must have an understanding of the disease and its symptoms and processes. Arthritis is a crippling disease, one that limits mobility and physical function (Gabriel, Crowson, & O'Fallon, 1999). Coping with the disease and its symptoms requires acceptance of the chronic disease (Holman & Lorig, 2004). The unpredictable disease symptoms make coping with this chronic disease difficult. For example, one community member who was recently diagnosed with rheumatoid arthritis posted the following:

I had to cancel my girls' night out tonight. My knees and ankles are swollen, so painful. I can't even touch my skin – it hurts too much. My friends think I'm ditching them with no real excuse. I hate this disease. Since no one can see my pain, no one ever thinks anything is wrong.  
(Arthritis Foundation)

Community members often had difficulty coping with arthritis and its symptoms when there was interference in their lives. More so, coping with this chronic disease was most challenging when the “off-line” world did not understand. Because arthritis is an “invisible” disease, meaning arthritis is not typically obvious to those who don't know about the disease or diagnosis; many people have misperceptions about arthritis. As illustrated earlier, arthritis is often attributed to only affecting the elderly. Social support networks “off-line” like family members or spouses did not always show empathy or

know how to address the diagnosis of chronic disease. For example, the following was posted on Creaky Joints:

I think my husband thinks I'm faking the pain. I was diagnosed almost a year ago and at first, he was so great. On my good days, I can handle everything [that she did before the diagnosis]. But it's my bad days that are really hard. My husband doesn't offer any extra help or support, even when it's obvious I am in pain. I wish he could live in my body for just one day.

Another example is one community member's post regarding recent flares in symptoms and her missed days at work:

I'm so upset. Really, I don't know what to do. I've been having a flare for... well, forever. I've been working with my rheumy on different combinations of medications, but nothing has helped. I have missed almost two week of work and don't know when I'll be able to go back. I have tried to explain my situation to him, but because I look normal... I don't think he thinks that I am sick. I don't know what to do. Any suggestions? (About.com)

Community members that have had the disease for a long period of time and that have experienced such employment issues encouraged others to "be their own advocate" because "no one else will be." The online health communities helped to promote patient advocacy and also encouraged members to participate in political and social issues surrounding disease and disability.

## **CHAPTER V**

### **DISCUSSION**

The purpose of this research was to examine the computer-mediated communication within online health communities to understand the role engagement plays in eHealth literacy and the perceived benefits, perceived barriers, and expressed feelings of self-efficacy toward self-management behaviors of people with arthritis. The new media landscape offers many resources for people with chronic disease, including health information and social support. Many online health communities offer disease-specific health information, but also a network of like-individuals diagnosed with the same disease. Patients that are members of these online health communities are seeking health information but some are also interested in sharing their experiences of disease. The members of these communities all share a common disease diagnosis and in the case of arthritis, many experience the same disease symptoms like pain, stiffness, and swelling of the joints. This research examined online health communities in regards to self-management behaviors of people with arthritis. Since formal, in-person arthritis self-management programs are underused (Theis, Helmick, & Hootman, 2007), but yet people with arthritis are managing their disease (Holman & Lorig, 2004), this research looked to peer-to-peer online communities for evidence of how people with arthritis use and define self-management behaviors. This research also examined the engagement of members in online health communities, specifically regarding the self-management behaviors found within the computer-mediated communication, and the



attitudes and feelings of self-efficacy related to these behaviors. Online health communities have the potential to offer resources that facilitate the “off-line” use of chronic disease self-management behaviors. This research took a “bird’s eye view” of online health communities to understand how people with arthritis use self-management.

A chronic disease like arthritis is challenging for patients to self-manage because of the unpredictability of its symptoms. Not knowing what to expect, including flaring symptoms and disease progression, interferes with patients’ psychological acceptance and/or adjustment to arthritis, often results in depression (Dickens & Creed, 2001; Katz & Yelin, 2001; Parker, Smarr, Slaughter, et al., 2003). The purpose of self-management is to educate patients on how to manage their disease, but also works to improve attitudes and feelings of self-efficacy related to the disease (Lorig, 1999). When a patient feels self-efficacious over his or her arthritis, the better self-management behaviors he or she will practice (Bandura, 1994). Evidence-based self-management programs address how to manage physical symptoms, psychological symptoms, but also facilitate health literacy regarding chronic disease. For patients with arthritis, the disease process must be understood in order to self-manage its symptoms. For example, patients must know what triggers their symptoms, what effects medications have on their symptoms, or how to cope emotionally with the unpredictability of the disease.

The first research question (**RQ1**) addressed how online health communities facilitate arthritis self-management. Across all four online communities, patients were in search of information or a source of personal experience for other members. While

patients might share similar experiences, arthritis affects patients differently and thus, problem-solving skills are necessary for self-management. The longer a patient has arthritis and copes with the disease, the more understanding her or she has of the disease and is better able to practice disease self-management. Online health communities provide resources, including personal experience, for people with arthritis. Members can read archived computer-mediated communication exchanged between peers, searching to meet their informational needs. This health information then becomes tailored for the needs of the patient seeking information. When one community member inquires about a new medication, other members that respond share different experiences and perspectives, adding to the inquiring patient's knowledge of the medication. Members also refer the inquiring member to specific computer-mediated communication shared earlier, maybe in a different thread. This knowledge becomes the patient's understanding of the disease, or health literacy of arthritis. Over time, the inquiring patient becomes familiar with the disease by means of experience and then transforms from inquiring to contributing. Members become "expert" patients and help to "school" the "novice" members.

In regard to the type of engagement online community members demonstrated (**RQ2**), this research specifically examined the frequency of participation, but also critical thinking, as proposed by Perkin and Murphy (2006). Across the four online health communities, members averaged more than three *visits* per week, though not always participating in the discussion. Visits here specifically refer to when a community member logs into the health community with his or her username and password. Across

the four online health communities, members averaged two posts per week, sampled posts averaging 57 words.

Beyond this initial assessment of engagement, Perkin and Murphy's (2006) categories (i.e., *clarification, assessment, inference, strategies*) were used to evaluate members' engagement with the computer-mediated communication. Across the four communities, *clarification* (42.2%) was the most frequent category reported, meaning simply that community members were stating or defining self-management behavior(s). This might have been in terms of seeking or sharing information. Information support has been found to be one of the benefits of participating in online health communities (Eysenbach, Powell, Englesakis, et al., 2004). The seeking and exchanging of information is the foundation of these online communities. Without the computer-mediated communication, no community would exist. Inherently, these members share many things in common – diagnosis, prescription medications, experiences related to disease, emotions – and when sharing information, they gain clinical knowledge from like-others (Eysenbach, et al., 2004; White & Dorman, 2001). An example here is of a new member inquiring about her newly-prescribed medications, asking for other members to share their experience(s) with the medication(s). Familiar members then respond with their personal experience and (perceived) knowledge of the medication. In some cases, community members include reference to medical or scholarly research. It makes sense here that clarification would be found in online health communities because, given the nature of computer-mediated communication, information is exchanged among members. In this case, information translates to experience or perception of self-

management behaviors. The next most identified category was *strategies* (29.8%). This is evidence of community members discussing ways to manage chronic disease. Since these patients with arthritis truly are the experts on the disease, it makes sense that members would exchange strategies to manage the disease. Examples of *strategies* include personal recommendation for Easy Spirit walking shoes, taking hot baths, and applying a homemade ointment to the inflamed joints. Some community members sought out strategies that have been successful for other members, and others shared their personal stories of success. Community members also made *assessments* (28%) of self-management behaviors. This is an assessment in regards to both self and others. Members assess their own symptoms and also offer assessment of other members' symptoms. The final category Perkin and Murphy (2006) use to define critical thinking is *inference*. *Inferences* were found in 10.2% of the sampled posts. As community members live with the disease and experience different medications and symptoms, they are able to make connections about what triggers their symptoms or aggravates their joints, as to avoid in the future. These *inferences* were unique to the individual and their experience.

Maintaining an increased quality of life means understanding the disease and practicing self-management by applying problem-solving skills to disease-related problems. Physicians prescribe medical treatment plans, but it is the responsibility of the patient to manage his or her own disease. Within these online health communities, members exchange health information in an effort to help like-others solve arthritis-related problems.

There are several implications for scholars and health professionals alike. First, online health communities provide opportunities for health communication researchers to examine patients' "language" and create messages that consider the context in which people understand and practice self-management behaviors. Second, this research defines engagement using Perkin and Murphy's (2006) categories of critical thinking (i.e., *clarification, assessment, inference, strategies*), which relates to patients' health literacy. Nutbeam's (2000) definition of health literacy includes "critical literacy," which he defines as an individual's ability to critically analyze health information and apply the knowledge learned to gain greater control over current life situations. Likewise, Zarcadoolas, Pleasant, and Greer (2005) argue that an individual's understanding of health evolves over time based on personal experience. Members' experience with disease and its affect on their lives provided an understanding regarding arthritis. Thus, an individual's knowledge of his or her disease is influenced by disease symptoms and/or disease stage.

Disease stage often dictated self-management behaviors. As noted earlier, symptom flares often dissuaded members from participating in exercise or even healthy eating. If members were not experiencing symptoms, often they fell victim to the "feel good syndrome," and overdid their physical activity causing a flare in symptoms. As community members became more familiar with their arthritis and its reaction to activity, they were able to make decisions as to what to participate in and to what measure. Problem-solving skills are important to the management of any chronic disease, especially arthritis (Lorig & Holman, 2003). Formal self-management programs

strive to teach patients with arthritis how to identify potential threats and make proactive decisions to avoid negative health outcomes (Theis, Helmick, & Hootman, 2007). By interacting with like-others in the online health community, members are able to “see” how other members manage their disease, including successes and failures, which help to modify their own behaviors. This has implications for health behavior change theories, particularly the social cognitive theory (Bandura, 1986). These online health communities showcase health behaviors through the exchange of computer-mediated communication with like-others.

There were differences in the four online health communities in terms of engagement. For instance, WebMD’s community members were the most engaged, followed by Creaky Joints, About.com, and the Arthritis Foundation. An explanation for this might be simply related to the popularity of WebMD. For instance, WebMD magazine is ranked as one of the top 50 U.S. magazines (MARS, 2010); and the WebMD website is well-known for self-diagnosis or treatment information. According to comScore (2007), WebMD is one of the top 10 most visited health websites in the U.S. Similar to WebMD, though not entirely related to health, About.com ranks as a popular source of health information for people in the U.S. (comScore, 2007). Both WebMD and About.com offer general health information on a variety of topics, including arthritis, in addition to the online health communities. Specific to arthritis are Creaky Joints and the Arthritis Foundation websites. Both offer in-depth information about arthritis and provide resources (e.g., medical services, philanthropic events) for people with arthritis. Creaky Joints is a grassroots non-profit organization that is based in New York and its

mission is to “bring arthritis to its knees.” Surprising is the engagement in the Arthritis Foundation community being last of the four health communities. The Arthritis Foundation is a health agency that offers information and tools for people with arthritis to live better lives. For full access of information, membership is required to this website although the online community is free. Research should examine the characteristics of each online health community and the features that entice members to participate. In short, researchers who want to examine and/or compare online health communities must account for the websites sampled, as differences can occur by mere selection of website alone. The theoretical implication is that online health communities may not be generalizable across disease diagnosis. More research should examine members’ engagement in specific online health communities (i.e., for-profit versus non-profit, mainstream versus grassroots organizations).

This network of people with similar disease diagnosis is more than a source of health information and experience; online communities are budding networks of advocates. The members seek out these communities and engage because of a chronic disease. The shared computer-mediated communication of self-management (**RQ3**) is evidence that these patients want to understand the disease and be able to successfully manage their symptoms. As the results indicate, 70% of the sampled posts contain at least one self-management behavior. Not only do the community members share a disease diagnosis, they also share the practice of managing the disease. Whether that means seeking more information on a particular medication, expressing frustration with the disease, encouraging exercise, or suggesting ways to communicate with the

“rheumy,” or rheumatologist, most of the computer-mediated communication is about self-management behaviors. Online health communities act as informal self-management programs for people with arthritis. Patients know their bodies and can evaluate themselves to understand what triggers symptoms or what alleviates pain. Having added perspectives and suggestions only helps these community members to be better patients.

Arthritis and rheumatic conditions are most often controlled by a combination of prescription medications (Lorig & Holman, 2003). *Drug management* (29.3%) and *symptom management* (22.7%) were frequently discussed within online health communities. With so many medications available to treat arthritis, it makes sense that community members would ask for personal experience of a particular medication. Because of the unpredictability of arthritis, it cannot be known what combination of medications will work, thus rheumatologists must sometimes experiment with different medications. Sometimes, however, medications do not successfully control the disease, resulting in a need for symptom management. This requires a patient to monitor his or her arthritis and proactively combat symptoms. Within the four online health communities, sharing strategies for symptom management was common, especially the exchange of strategies from expert members to novice members. A patient turning to other patients for experience is preferred for these community members. Hurried physicians may not be answering patients’ questions or may be seen as less credible than online community members. Through the exchange of computer-mediated communication of self-management behaviors, these members are engaging in social



support. Discussion of *social support* (26.6%) was common in these communities. The members within the online health communities act as a social support network for other members with arthritis. The common understanding of living with arthritis is the connecting fibers of the online communities. Theoretically, this means that shared medical characteristics may contribute to positive medical outcomes (i.e., better disease self-management), as others in similar situations may be able to offer pertinent advice and suggestions as well as social support. The exchanged computer-mediated communication examined here offers insight into the potential value of patients sharing health information through disease experience.

Community members also exchanged computer-mediated communication regarding effective *communication*. Communicating about an abstract disease that is not completely understood by the medical community poses challenges for people with arthritis (Parker, Smarr, Slaughter, et al., 2003). Sharing experiences of miscommunication or lack of communication with spouses and family members was common in these online health communities. For female community members who were diagnosed mid-life, communication was especially difficult. These women often had young children and felt overwhelmed by responsibilities they could no longer perform. The psychological guilt and frustration was “vented” within the online community and other members with similar feelings shared their experiences and strategies for overcoming these barriers. Community members also discussed strategies for communicating with physicians. Across all four communities, members shared grievances of the difficulty in seeing a specialist like a rheumatologist. Appointments

had to be scheduled months out in order to see a rheumatologist and often, the community member expressed dissatisfaction with the results of the appointment. Strategies were often exchanged for choosing a rheumatologist and communicating symptoms to the rheumatologist. Many members felt as if they did not receive sympathy or understanding from their physician, which often influenced their attitudes and feelings of self-efficacy toward self-management behaviors. What this means for researchers who want to understand the role of self-efficacy toward self-management behaviors is that expressed self-efficacy “off-line” may differ than that expressed within the online health communities. In patients’ “off-line” worlds, they may not know anyone personally who shares the same disease diagnosis and thus, do not express the same feelings of self-efficacy as those expressed within the online health communities among like-others. Feelings of self-efficacy may differ based on patients’ perception of “sharedness” which has implications for source credibility of health information.

There was computer-mediated communication within the online health communities that contained evidence of *psychological consequences* (6.9%) or *lifestyle factors* (9.3%), though not common. Often, community members lived in the moment of the disease. For example, if they were experiencing a flare in disease symptoms, their outlook or attitude toward self-management behaviors tended to be negative. Although the post may have been coded as “negative attitude,” if no direct mention of emotion or feeling was present within the post, evidence of psychological consequences was not found to be present. The lack of computer-mediated communication about psychological consequences might also be explained by the stigma surrounding mental

health. Medical research has found that people with arthritis fear long-term pain, stiffness and fatigue; and they also have concerns about loss of function, work disability and the possible socio-economic effects of the disease (Katz & Yelin, 2001). The potential “toxicity of long-term treatment with disease modifying agents” is of concern for people with arthritis (Parker, Smarr, Slaughter, et al., 2003, p. 768). Although patients with arthritis may share these feelings, little computer-mediated communication addressed the psychological consequences of the disease. The theoretical implication is that online health communities help manage the psychological consequences of the disease through members’ exchange of computer-mediated communication. The act of exchanging health information and/or disease experience facilitates coping with the chronic disease.

Mention of *lifestyle factors* (9.3%) in regards to self-management was also notably absent from the online health communities’ computer-mediated communication. Most evidence was regarding strategies for physical exercise, like walking or swimming. Perhaps *lifestyle factors* were not discussed because drug management or symptom management topics take precedence over communication strategies or emotions and feelings for these community members. Research shows that exercise has positive effects on arthritis, including improving strength and flexibility and reducing painful symptoms (Theis, Helmick, & Hootman, 2007). There has been a misconception among people with arthritis that instead of improve disease symptoms exercise actually causes a flare in symptoms (Theis, Helmick, & Hootman, 2007). It may be possible that the community members sampled do not engage in physical exercise or

simply do not think such is important enough to share with others. Researchers can use these results to improve patients' knowledge of *lifestyle factors* that may affect arthritis symptoms.

Although self-management behaviors were common in the computer-mediated communication, there were differences found among the four online health communities. Overall, WebMD contain the most computer-mediated communication of self-management behaviors, followed by Creaky Joints, About.com, and the Arthritis Foundation communities. This pattern is reflective of members' engagement in the online health community. The members in the WebMD health community are the most engaged and also discuss the most self-management behaviors. It makes sense that the more a community member is engaged, the more information about his or her life experiences is shared with other members.

As people with arthritis learn more about their disease and have success managing the symptoms, their feelings of expressed self-efficacy increase. Self-efficacy was examined in regards to Bandura's (1994) definition, including *mastery experience*, *vicarious experience*, and *verbal persuasion* (**RQ4**). Mastery experience was most common, followed by verbal persuasion and vicarious experience. On its face, it makes sense that mastery experience would be seen most often in the online health communities because members are sharing their personal experience, rather it be a misstep or triumph with self-management behaviors. Mastery experience is the most influential source for predicting behavior (Bandura, 1994). Members engage in tasks and activities related to self-management, interpret the results of their actions, use those

interpretations to develop beliefs about their capability to engage in subsequent self-management behaviors, and act in accordance with the beliefs created (Bandura, 2004). Usually, behaviors successfully performed increase self-efficacy and failures decrease self-efficacy. There are theoretical implications for applying health behavior change theories (e.g., theory of reasoned action, health belief model, social cognitive theory) to the prediction of health behaviors. Self-efficacy is necessary to initiate health behavior change and thus may be used strategically in computer-mediated communication within online health communities to facilitate self-management behaviors.

People also develop beliefs about self-management behaviors based on vicarious experiences of others. More than 20% of the posts contained evidence of *vicarious experience*. It makes sense that people share their own experiences with the community, and although they may “see” others’ successes/failures with self-management, it is a limitation of this research to know if behaviors were performed “off-line” because of *vicarious experience*. *Vicarious experience* is especially influential when members see similarities in others and think the others’ performance is indicative of their own ability (Bandura, 1997). Observing the successes of others contributes to a member’s beliefs about his or her own capabilities. Conversely, watching others fail can undermine the observing member’s beliefs about his or her own ability to succeed. More research should examine self-efficacy within these online communities to understand the patient’s perception regarding their beliefs in practicing self-management behaviors. Online health communities have theoretical implications for the social cognitive theory, which posits that people learn behaviors by observing others

(Bandura, 1986). In the case of online health communities, the exchange of health information and/or disease experience acts as “patient testimonials” for what was successful and what was not in regards to self-management behaviors. Thus, members learn self-management behaviors by “observing” others’ experiences.

*Verbal persuasion* is also important to member’s participation in self-management behaviors. These persuasions involve exposure to the verbal judgments that others provide in the computer-mediated communication. Persuaders play an important part in the development of an individual’s beliefs about him or herself. Positive persuasions may work to encourage and empower, while negative persuasions can work to defeat and weaken self-efficacy (Bandura, 1995). This research did not examine the positive or negative verbal persuasions, but rather simply the presence of *verbal persuasion* (28.2%). Members used their own experience of the disease to persuade other members to practice self-management behaviors. Since many members come to the online health community in search of information about the disease and its symptoms, it stands to reason that these members either want to be persuaded or want to persuade. The online health community is about sharing information and personal experience.

Interestingly, there were differences among the four communities regarding self-efficacy. Again, WebMD contained the post evidence of self-efficacy, followed by Creaky Joints, Arthritis Foundation, and the About.com communities. Community members’ self-efficacy improved following success of a self-management behavior, whether influenced by vicarious experience or verbal persuasion. The computer-mediated

communication within the online health communities might be thought of as a guide to managing arthritis, written by patients for patients. Members are sharing “tricks” to managing arthritis symptoms in order to help others in a similar situation. Most members “figure it out” with trial-and-error. Self-management behaviors are not the same for every member with arthritis. Members have to develop an understanding of their arthritis and its affect on their lives. Self-management behaviors are categorized as being broad (e.g., symptom management, communication) because patients have to become the “expert” of the disease and use problem-solving skills to manage its symptoms and affect.

A relationship between engagement and self-efficacy (**RQ6, RQ7**) was seen within the four online health communities. The more engaged a community member is with the computer-mediated communication, the more feelings of self-efficacy toward self-management behaviors were expressed. Disease stage often influenced a member’s feelings of self-efficacy and even self-management behaviors. When community members were experiencing a flare, their feelings of self-efficacy decreased. However, once the flaring symptoms subsided, their feelings of self-efficacy improved and they then shared their experience with the health community. In regards to health behavior change, these online health communities “model” health behaviors through the computer-mediated communication for other members to “see.”

Feelings of self-efficacy are also influenced by the perceived benefits and perceived barriers to participating in self-management behaviors (Fishbein & Ajzen, 1975). Overall, community members discussed more benefits to practicing self-

management than barriers. For example, community members see benefits to taking prescription medications like less active disease symptoms. But for some, *perceived barriers* might exist. One community member posted the following in regards to taking her medication:

I hate sticking myself [with the medication injection] every week. I bruise every time. I just hate it. I suffer enough... and now, I have to stick myself every week? (About.com)

Experience with the disease often changes patients' perceptions of *perceived benefits* and *perceived barriers*. Months after the community member posted the above about the prescription injection, she instructed a new community member how to administer the injection so it did not leave a bruise:

I think the best thing to do is think of the needle like a dart. Do you ever play darts? You know the motion of the quick snap when throwing a dart? Think of the needle that way. Just count to three, breath in and when you get to three, throw the dart. Quick snap. If you can get that, you won't see any bruising. Just remember to throw the dart. (About.com)

Thus, this community member no longer perceived barriers to injecting the medication and used her own experience to educate (or, verbally persuade) other members with her own success story. There are theoretical implications here for predicting health behavior based on patients' feelings of self-efficacy. Health communication regarding arthritis self-management should seek to emphasize patients' perceived benefits to practicing particular self-management behaviors. Patient education should seek to educate patients as to how to overcome perceived barriers to participating in arthritis self-management behaviors. Research should use the "language" found within these online communities to address the perceived barriers of self-management.



Community members' perceptions changed as their disease changed. With rheumatoid arthritis, change in symptoms is unpredictable and occurs sporadically. Flaring symptoms cause members to post computer-mediated communication with perceived barriers to self-management behaviors. However, these perceived barriers are overcome as the disease symptoms subside. Once symptoms are in control and the community member is feeling better, perceived benefits are found in relation to self-management. Thus, disease stage might be thought to influence the perception of benefits/barriers to practicing self-management behaviors. Additionally, personal experience with arthritis also eliminated perceived barriers to practicing self-management. For example, a newly diagnosed member perceived more barriers to drug management (i.e., side effects, cost) than "expert" members familiar with the consequences of not taking the appropriate prescription medication. Experience influences members' perceptions of self-management behaviors, which relates to health literacy and patients' development of problem-solving skills.

This research also examined the health literacy of online community members **(RQ8)** in regards to arthritis self-management. Health literacy evolves over time based on a number of factors, including health status and personal experience (Zarcadoolas, Pleasant, & Greer, 2005). The computer-mediated communication within the online communities provides opportunity for members to interact with information, but also to tailor such information to their personal needs or current situation. Members are able to derive personal meaning from the computer-mediated communication within these online communities, which Nutbeam (2000) termed interactive health literacy, but also

to share personal experience and knowledge in an effort to contribute to the larger disease narrative of the online health community. “Expert” patients are familiar with their arthritis and its symptoms, including the disease affect on their lives, and the self-management behaviors necessary to reduce such disease affect. As members experience situations related to their arthritis, they employ problem-solving skills in order to make decisions to enhance individual quality of life.

Additionally, these online health communities related to arthritis are examples of *eHealth literacy* (Norman & Skinner, 2006) in that the members are seeking and exchanging health information using eHealth resources. These members are motivated to become “expert” patients through consumption of information generated by like-others. Patients are using the online health communities to seek and exchange health information, but also as a means to understanding disease, and coping with its affect. As mentioned previously, eHealth literacy shares similar “literacies” as other scholars’ definitions of health literacy (Nutbeam, 2000; Zarcadoolas, Pleasant, & Greer, 2005). These definitions of health literacy are rooted in knowledge and understanding at the individual-level, and seek to empower individuals and enable them to participate in health decisions. Online health communities offer members information from various perspectives, from people with arthritis at different disease stages that have different disease prognoses and experiences. Additionally, the online health communities provide members the opportunity to interact with information and like-others. This interactivity increases members’ understanding of the disease and self-management behaviors. The gain of knowledge and understanding from the computer-mediated communication

generated by like-others facilitates problem-solving skills and transforms patients into decision-makers.

### **Practical Implications**

There are number of practical implications for health care communicators and professionals who want to address the issue of self-management among people with arthritis. First, health care communicators can use the results to create strategic health messages that promote health literacy of self-management behaviors from a patient's perspective. Second, people with arthritis are practicing self-management behaviors, though not attending formal programs. Participation in online health communities by health care professionals and patient educators may improve understanding of the disease – as experienced by the patient. Additionally, online health communities may give insight into how to “speak” to people with arthritis regarding the disease and self-management behaviors. Likewise, online communities provide opportunity for health care professionals to develop empathy and understanding of the psychosocial consequences of arthritis. This could help improve physician-patient communication, including patient compliance to medical treatment programs.

Pharmaceutical and insurance companies may also find opportunity within online health communities to increase patient knowledge of chronic disease and self-management behaviors in an effort to reduce the monetary impact of chronic disease on the economy. However, ethical consequences should be explored before either industry participates in the online health communities. It might be evaluated as to the cost-effectiveness of online health communities in regards to patient care. Online health

communities may provide opportunity for early detection of arthritis symptoms and prevention of disease affect, including joint deformities and immobilization. Early detection of arthritis symptoms can help lessen disease affect on patient's lives, including joint deformities and depression.

The full potential of online health communities must be realized. Imagine the opportunities that exist in patient care. For example, online health communities could be used for administering out-patient physical and occupational therapy. Therapists could create a video demonstration of the exercise and be available to answer questions from patients within the online community. Patients then could engage in the "off-line" behavior and later discuss his or her experience within the community. The online health community might also act as a reminder to administer medication properly. This might include a visual that instructs patients how to inject a medication subcutaneously. Of course, online health communities cannot replace health care professionals, but might be used as an extension of medical services.

### **Limitations and Directions for Future Research**

This study is not without limitations. This research employed both a content analysis and an ethnomethodology. However, these methods are not able to establish causality, nor are any claims of causal relations made in this research. Future studies can attempt to establish causality by conducting the appropriate methods and analyses. Future research may examine the "off-line" effects engagement with the computer-mediated communication has on members and their self-management behaviors, attitudes and self-efficacy of the disease. Additionally, future research might address

how engagement with self-management behaviors influences the practice of such behaviors, but also the long-term impact of engagement on self-management of the disease.

The findings of this study are specific to arthritis and cannot be generalized across chronic diseases. More research should examine online health communities dedicated to other chronic disease to determine what extent self-management behaviors are being discussed and how such behaviors are being used by people with chronic disease. Some self-management programs are not specific to a particular disease, and online health communities might provide detail as to how self-management for various chronic diseases differs.

Research should also seek to evaluate members' experiences within the online health community. Interaction with like-individuals is happening within the online health communities, but research should examine the effect of such interaction on self-management behaviors. Future research should also examine how a patient's health literacy is influenced by disease experience. Specifically related to arthritis, disease stage (e.g., newly diagnosed, active, flare) should be examined and its effect on members' engagement with computer-mediated communication of self-management behaviors.

Future research might explore these online health communities further as informal patient self-management programs and how they might be used to complement the health care system. For instance, how might an online community become an extension of the medical office experience with a specialist, like a

rheumatologist? Research should examine why members are participating in the online health community and what effect the participation has on their “off-line” worlds, including the practice of self-management behaviors. Additionally, research should explore if community members desire contribution by health care professionals or if it is the peer-to-peer information and environment that makes these online health communities desirable.

Research should also examine the role of self-efficacy in online health communities and what “off-line” effect mastery experience, vicarious experience, and verbal persuasion have on members’ self-management behaviors. It might be further examined as to how these online health community members “model” self-management behaviors for other “novice” members. Future research should qualitatively examine the perceived benefits and perceived barriers to arthritis self-management. Such knowledge might inform future health education and promotion regarding arthritis self-management programs.

In regards to the stigma related to mental health, online communities should be examined for clues of depression, as Dickens and Creed (2001) argue depression is frequently misdiagnosed in people with arthritis. Physicians are too hurried to recognize the signs of depression, and this might be the reason people with arthritis turn to the Internet for support. Like others have experienced similar emotions and feelings related to living with a chronic disease and are thus able to understand. More research should address how online health communities are used to address depression among people with rheumatoid arthritis.

Research should examine the potential of pharmaceutical sponsorships. As shown, community members are already discussing their prescription medications in detail, including generic medications, dosages, and side effects. Research should examine the accuracy of the health information exchanged by peers within these online health communities. Also, it might be asked how online health communities might be utilized for patient education and improving health literacy of chronic disease self-management.

The proliferation of these online health communities provides opportunity for health communicators to tailor messages and utilize these communities for education regarding self-management. Continued research is needed to further examine the role of online health communities in increasing members' self-efficacy, compliance with self-management behaviors, and health literacy regarding chronic disease. In addition, further research is needed to understand the unique characteristics of those people who engage in online health communities and what influence engagement in the community has on "off-line" self-management behaviors.

Last but not least, it was clear from these findings that the website, or online community, being examined *makes* a difference in terms of the types of information and knowledge relayed in the individual postings of users of those online communities. The larger issue is that, to date, no schema exists on website type among online health communities. Clearly, there are differences due to whatever factors are emerging within these sites. The current research was aimed at identifying and analyzing the individual postings of individuals in these websites and not identifying factors of a given website.

Attempts to distinguish among types of online communities have been undertaken (Rodgers & Chen, 2005; White & Dorman, 2001; Wright, 2001). However, it is logical that future studies can undertake the task of conceptualizing a robust schema that accounts for type of online community and factors of importance within those communities.



## **CHAPTER VI**

### **CONCLUSION**

Chronic disease is an epidemic in the United States, affecting one in two adults (CDC, 2000). Arthritis affects one in five adults and is the leading cause of disability (CDC, 2009). People with arthritis often have at least one other chronic disease diagnosis (CDC, 2000). Thus, for people with arthritis, chronic disease self-management is essential (Lorig & Holman, 2003). And as new media technologies become more prevalent, people with arthritis and other chronic disease develop eHealth literacy skills in order to participate in the seeking and exchanging of health information and personal experience. The purpose of this research was to examine the computer-mediated communication within online health communities to understand the role engagement plays in eHealth literacy and the perceived benefits, perceived barriers, and expressed feelings of self-efficacy toward self-management behaviors of people with arthritis. The multi-method approach used here was useful in providing a snapshot of the patient perspective of chronic disease in an unobtrusive manner. The patient perspective gives insight into how people with arthritis manage their disease; and how online health communities in the new media landscape provide the resources necessary to facilitate such health behavior for people with chronic disease.

These online health communities act as informal self-management “programs” led by peers with the same chronic disease through the exchange of health information based on experience. Experience posted by members offers a plethora of topics and

perspectives by people with a shared diagnosis of arthritis. Personal experience demonstrates self-efficacy and might be thought of as “modeling” of self-management behaviors. Such exchange of information could be thought of as verbal persuasion by experience to influence other members’ practice of self-management behaviors. The more community members engaged in the community, the more feelings of self-efficacy were expressed. The sharing of information empowers members to engage in the exchange of experience with self-management behaviors.

Perkin and Murphy’s (2006) definition of engagement is tied to critical thinking. This is related to health literacy (Nutbeam, 2006). Patients must critically analyze health information, including the accuracy and credibility. This research did not examine the accuracy of the computer-mediated communication found within the online health communities. Instead, the personal experience of these members evoked a sense of “sharedness” among other like-others in which self-management behaviors could be discussed. Knowing that others in the community share the disease and have thoughts and opinions on a particular self-management behavior allows for an immediate discussion of knowledge and experience related to that particular behavior. Members are able to be candid, though this is perhaps not obvious to “outsiders,” or people who do not have arthritis. Ethnomethodological analysis provided patient “speak” that instigates the sense of “sharedness” within each online community. There is no need to define terms or references because the like-others within the community understand the code.

There is much to be learned from these online health communities, especially related to health behavior change. The computer-mediated communication exchanged within these communities provides opportunity to predict health behaviors and examine patients' attitudes and perceptions regarding health behaviors. Health behavior change theories like the Theory of Reasoned Action or the Health Belief Model could be examined in the context of online health communication among patients regarding specific behaviors.

Patients are actively seeking out these online health communities in search of support, whether informational support or social support. Online communities provide opportunities for health behavior change messages to educate and persuade regarding arthritis self-management behaviors. It is evident from this research that people with arthritis want to discuss self-management, freely sharing experiences and information related to these behaviors. It might be considered how these online health communities could be used to improve self-management behaviors and minimize the impact of arthritis on their members. Members want to avoid the painful symptoms of arthritis and seek alternate opinions and perceptions regarding strategies to do so. Then, based the computer-mediated communication offered by like-others, members use problem-solving skills in order to best apply the shared information to their current situation. The idea of problem-solving then is a component of health literacy.

If we ever hope to tackle the “silent epidemic” that is chronic disease, we have to learn the patients’ language. Patients are engaging in online health communities with like-others in order to exchange health information and disease experience. These

communities provide an opportunity to include the patients at the roundtable discussion on patient care and self-management of chronic disease.

## CHAPTER VII

### APPENDIX

*Online health community member profiles, ethnographic field notes*

About.com

Member #1 - Female - 32 YO	Diagnosed with RA in 2007; Fibromyalgia in 2009	Arava, Plaquenil, Naproxen, Prednisone
Member #2 - Female - 53 YO	Diagnosed with RA in 1987	Humira, Naproxen, Plaquenil, Prednisone
Member #3 - Female - 41 YO	Diagnosed with RA in 1999; OA in 2000; Type II diabetes in 2005	
Member #4 - Male - No age reported	Diagnosed with RA in 1992; Lupus in 2003	Remicade infusions, Plaquenil, Naproxen
Member #5 - Male - 83 YO	Diagnosed with RA in 1998	Methotrexate, Arava, Plaquenil

Arthritis Foundation

Member #1 - Female - 43 YO	Diagnosed with RA in 1990	Humira, Naproxen
Member #2 - Female - 65 YO	Diagnosed with Fibromyalgia in 2009	Cymbalta, Prednisone
Member #3 - Female - 42 YO		
Member #4 - Female - No age reported	Diagnosed with RA in 2010	Enbrel
Member #5 - Female - No age reported	Diagnosed with RA in 1998	

### Creaky Joints

<b>Member #1</b> - Male - 39 YO	Diagnosed with RA in 2005	
<b>Member #2</b> - Female - 47 YO	Diagnosed with RA in 1998	
<b>Member #3</b> - Female - 36 YO	Diagnosed with RA in 2005; Fibromyalgia in 2006; Depression in 2009	
<b>Member #4</b> - Female - 50 YO	Diagnosed with RA in 2001	Actemra, Naproxen, Prednisone
<b>Member #5</b> - Female - 62 YO	Diagnosed with OA in 2000; RA in 2007	

WebMD

Member #1 - Male - 46 YO	Diagnosed with RA	
Member #2 - Female - 27 YO	Diagnosed with RA in 2009	
Member #3 - Female - 45 YO	Diagnosed with RA in 2008	Methotrexate, Naproxen, Plaquenil
Member #4 - Female - 58 YO	Diagnosed with RA in 2003	
Member #5 - Male - 51 YO	Diagnosed with RA in 1997; OA in 2003	Simponi, Plaquenil, Naproxen



## CHAPTER VIII

### TABLES

Table 2. *Means of engagement by online health community*

Health Community	Mean	Standard Deviation
About.com	1.06	.91
Arthritis Foundation	.88	.83
Creaky Joints	1.36	.91
WebMD	2.37	1.25
Total	1.11	1.02

Table 3. *One-Way analysis of variance (ANOVA) results for the effect of community on engagement*

	Sum of Squares	Df	Mean Square	F	$\eta^2_p$
Health Community	453.06	3	151.02	184.52***	.22
Error	1,600.87	1956	.818		
Total	4,452.00	1960			

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Table 4. *Means of self-management behavior by online health community*

Health Community	Mean	Standard Deviation
About.com	1.33	1.22
Arthritis Foundation	1.12	1.13
Creaky Joints	1.88	1.51
WebMD	2.94	1.65
Total	1.40	1.37

Table 5. *One-Way analysis of variance (ANOVA) results for the effect of community on self-management behavior*

	Sum of Squares	df	Mean Square	F	$\eta^2_p$
Health Community	699.57	3	233.19	152.43***	.19
Error	2,992.354	1956	1.53		
Total	7,500.00	1960			

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Table 6.  
*Means of self-efficacy by online health community*

Health Community	Mean	Standard Deviation
About.com	.81	.78
Arthritis Foundation	.91	.90
Creaky Joints	1.26	.92
WebMD	1.57	.94
Total	.99	.92

Table 7.  
*One-Way analysis of variance (ANOVA) results for the effect of community on self-efficacy*

	Sum of Squares	df	Mean Square	F	$\eta^2_p$
Health Community	103.09	3	34.36	43.14***	.06
Error	1,557.83	1956	.80		
Total	3,595.00	1960			

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

## CHAPTER VIII

### FIGURES

*Figure 1.* Mean score for engagement in online health communities.

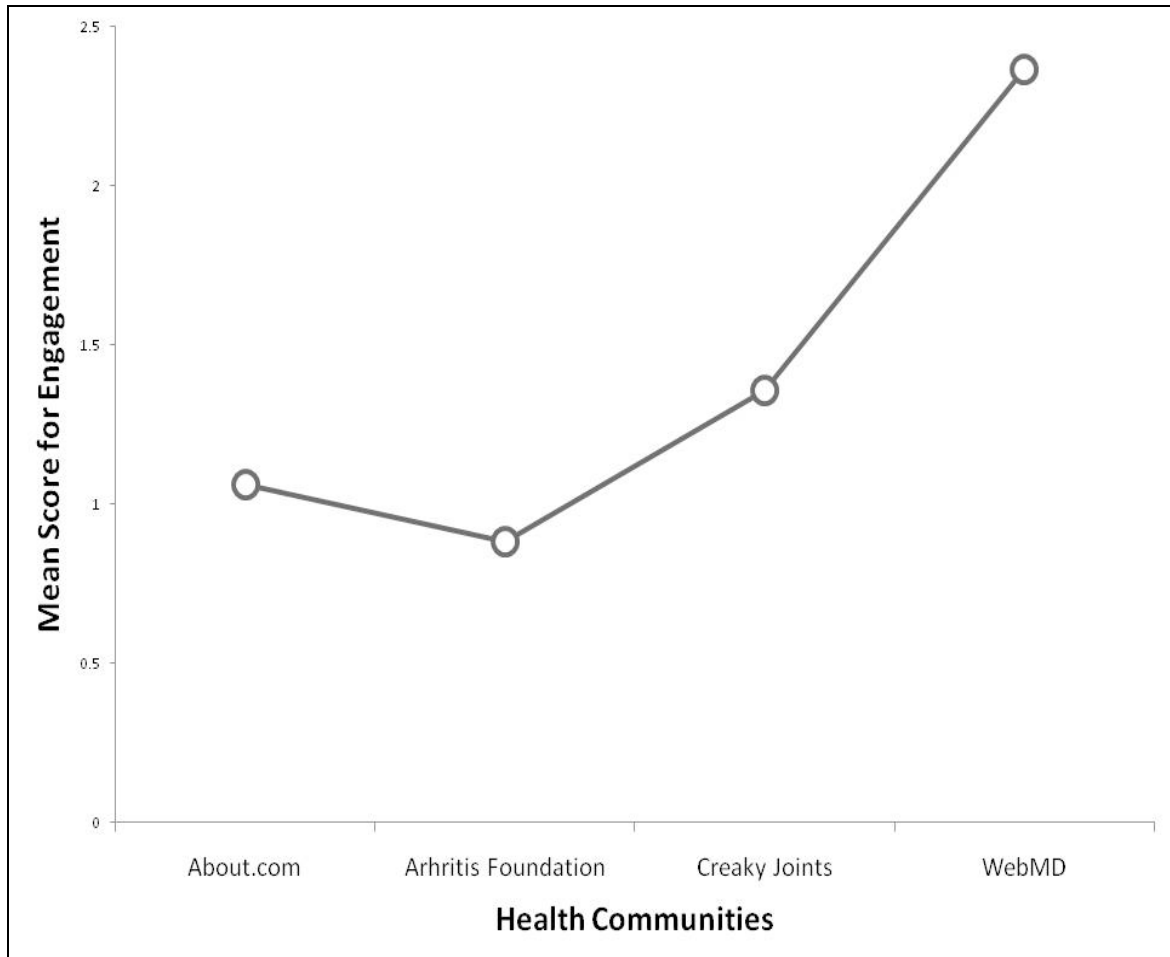


Figure 2. Mean score for self-management in four different health communities.

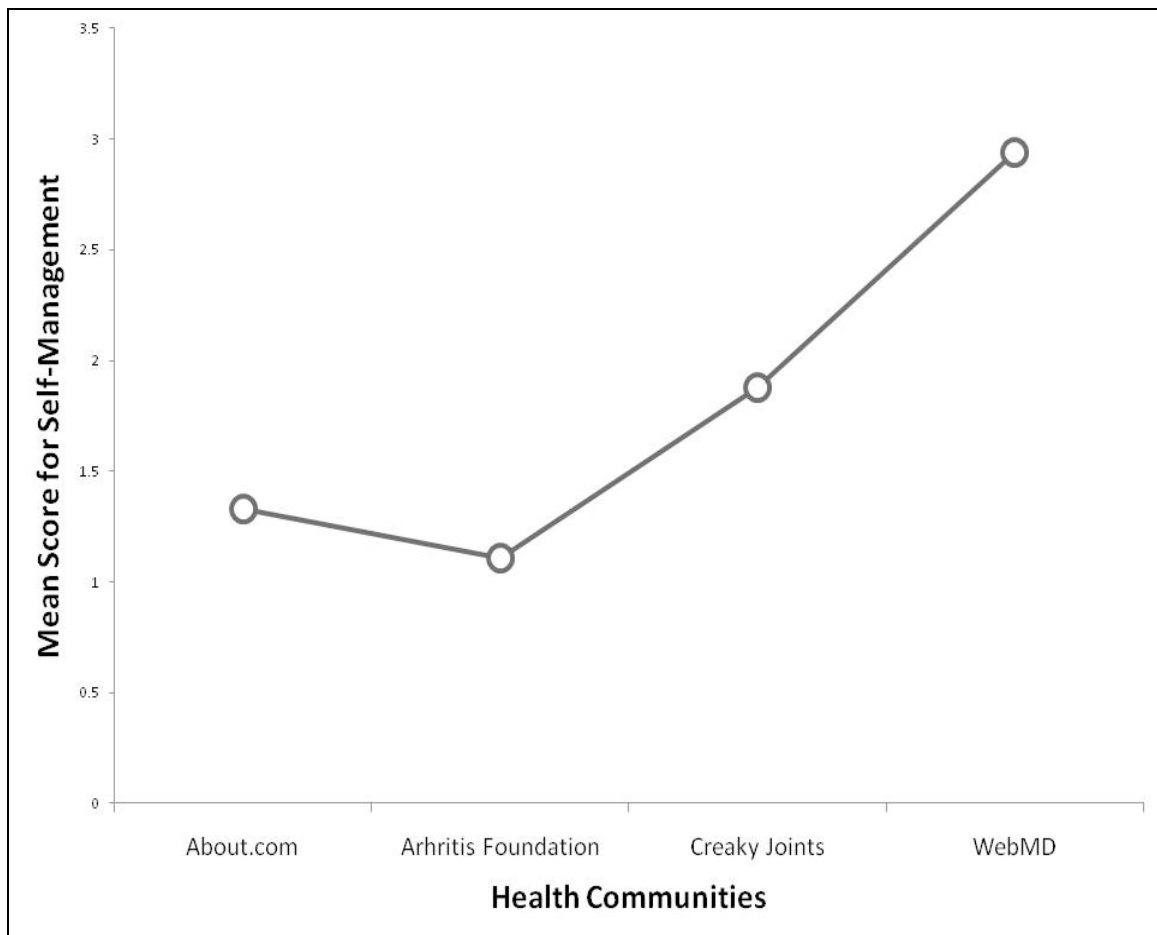


Figure 3. Percentage of cases that were coded as information within each community.

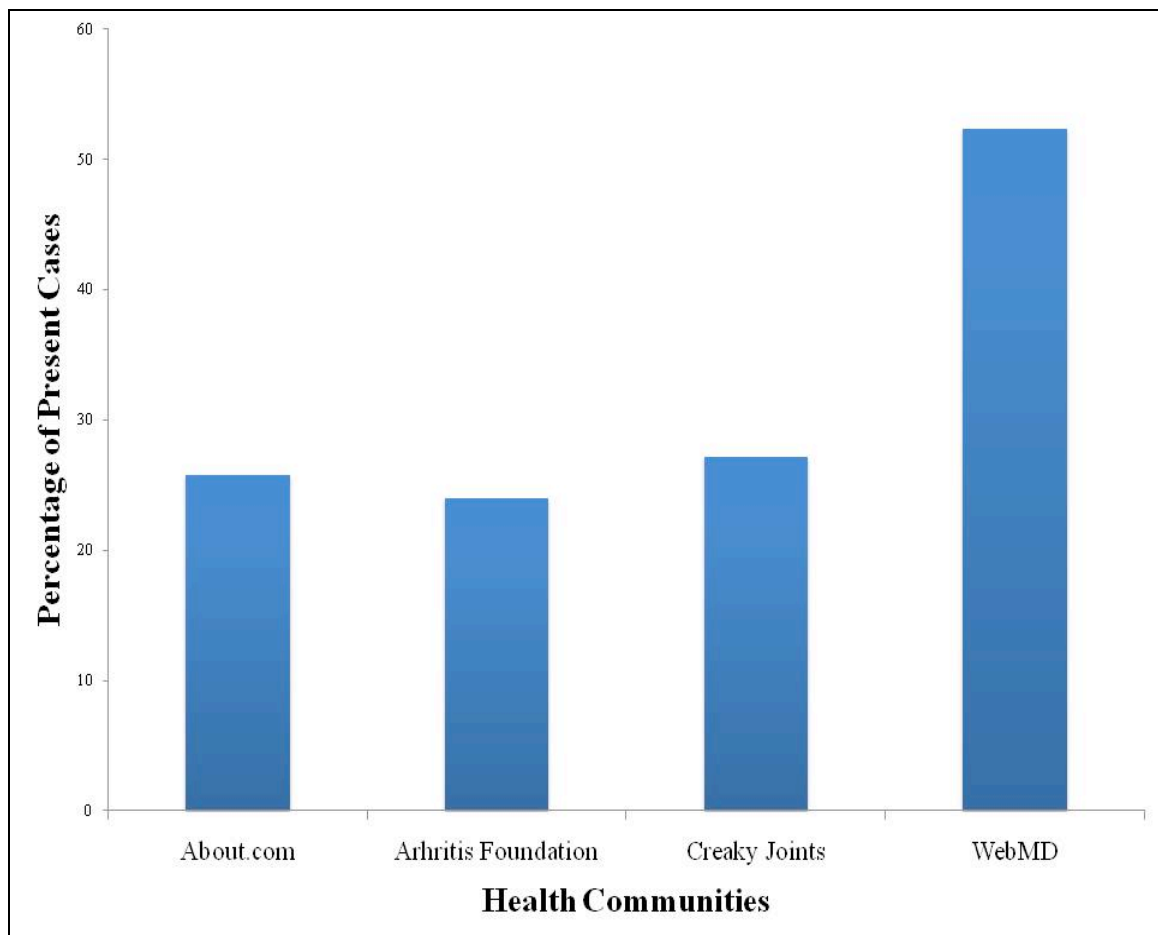
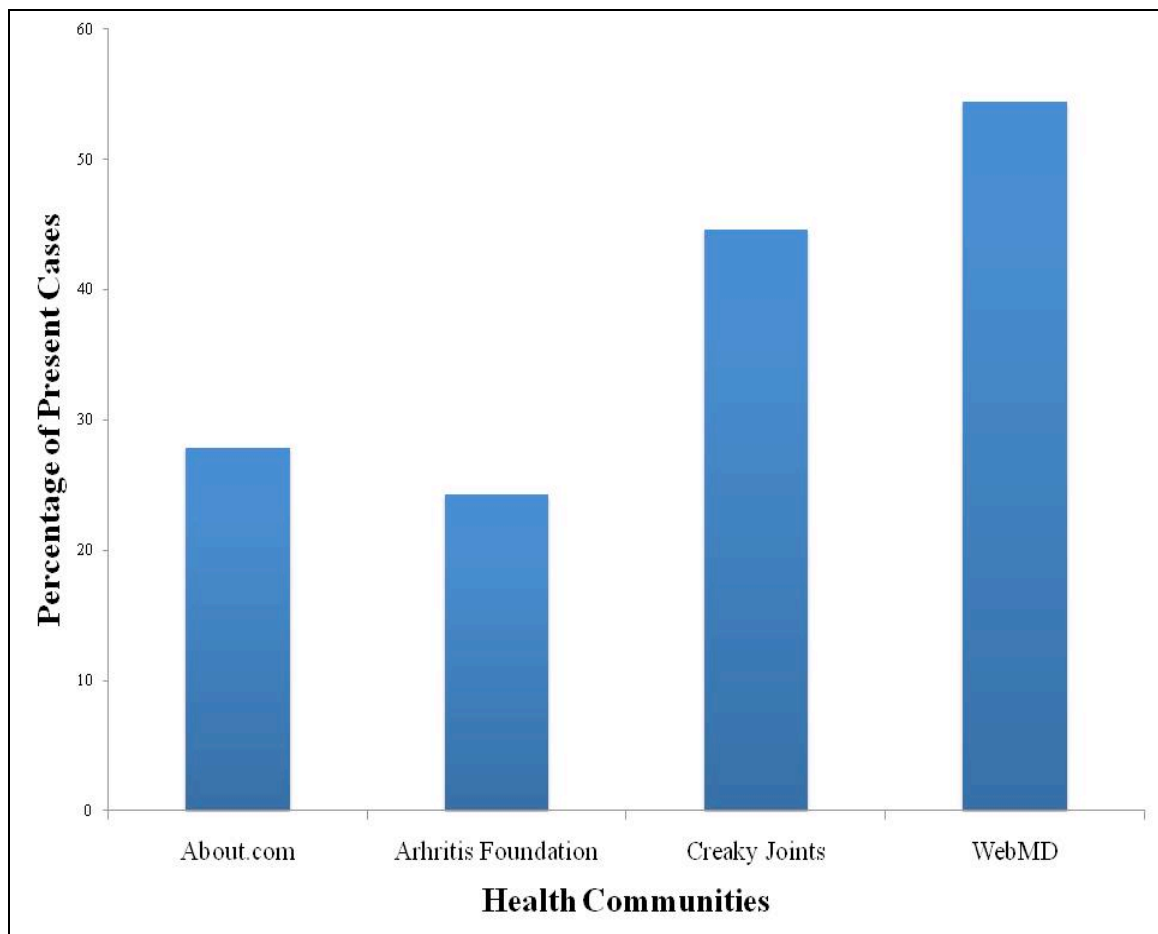
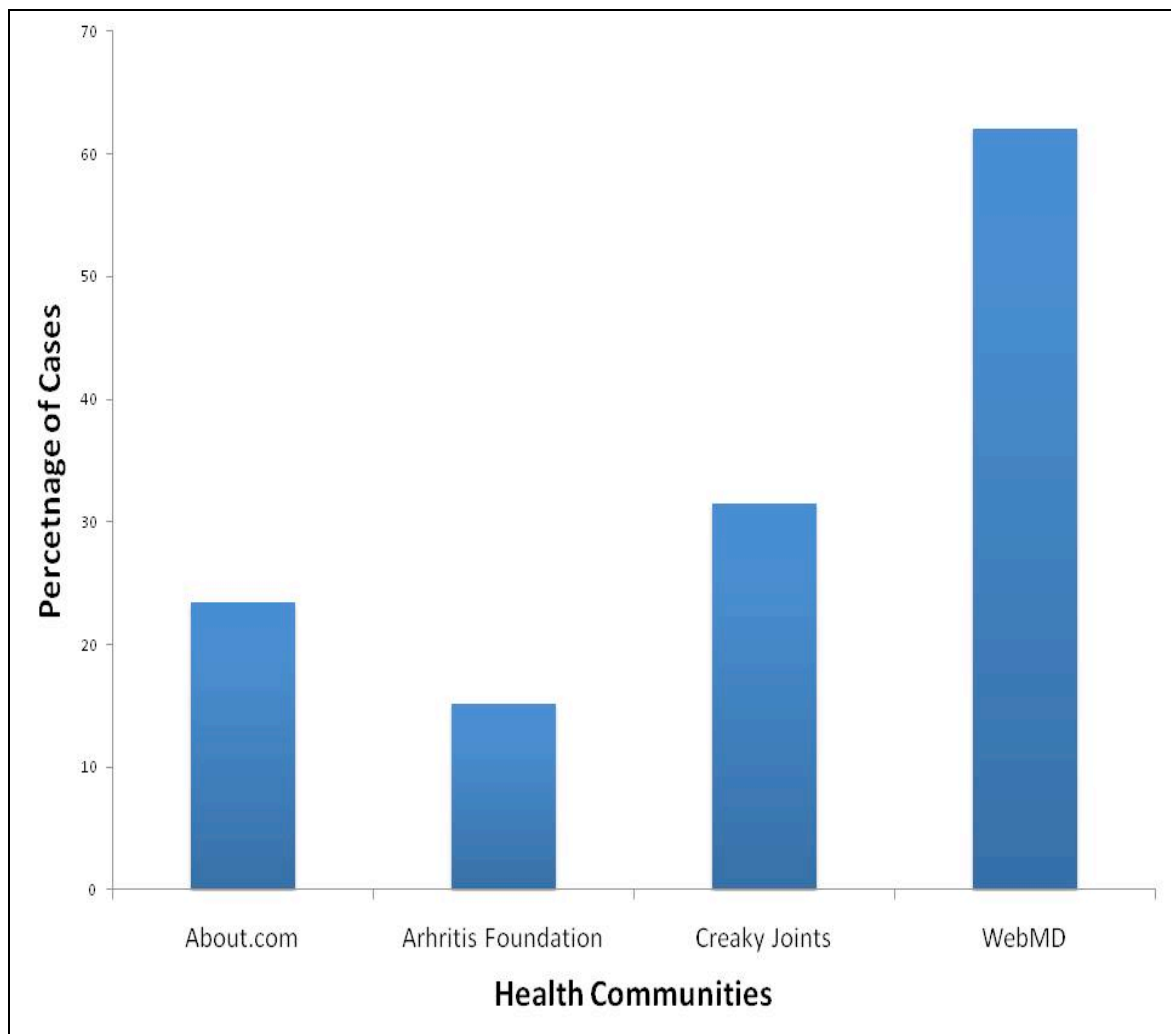


Figure 4. Percentage of cases that were coded as drug management within each community.



*Figure 5.* Percentage of cases that were coded as symptom management within each community





*Figure 6.* Percentage of cases that were coded as psychological consequences within each community.

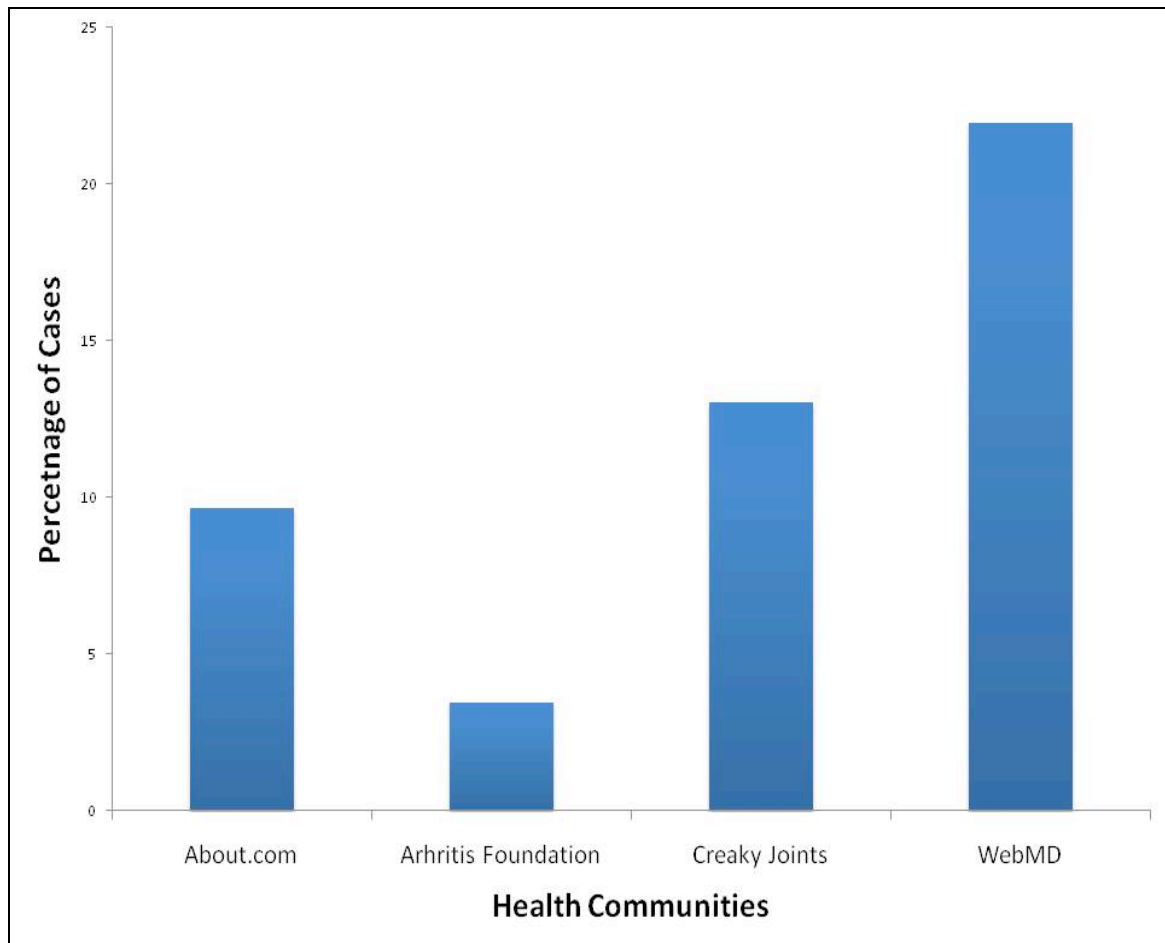


Figure 7. Percentage of cases that were coded as lifestyle within each community.

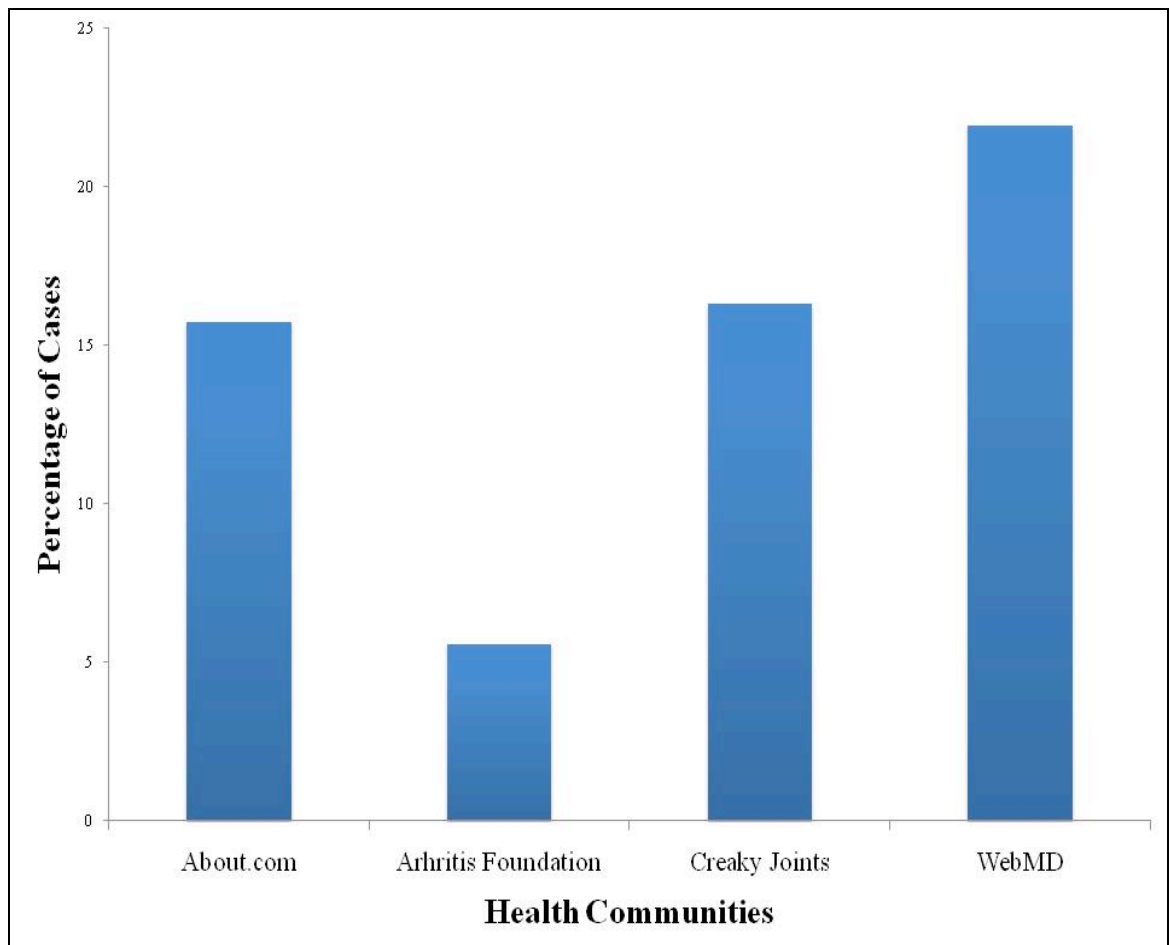
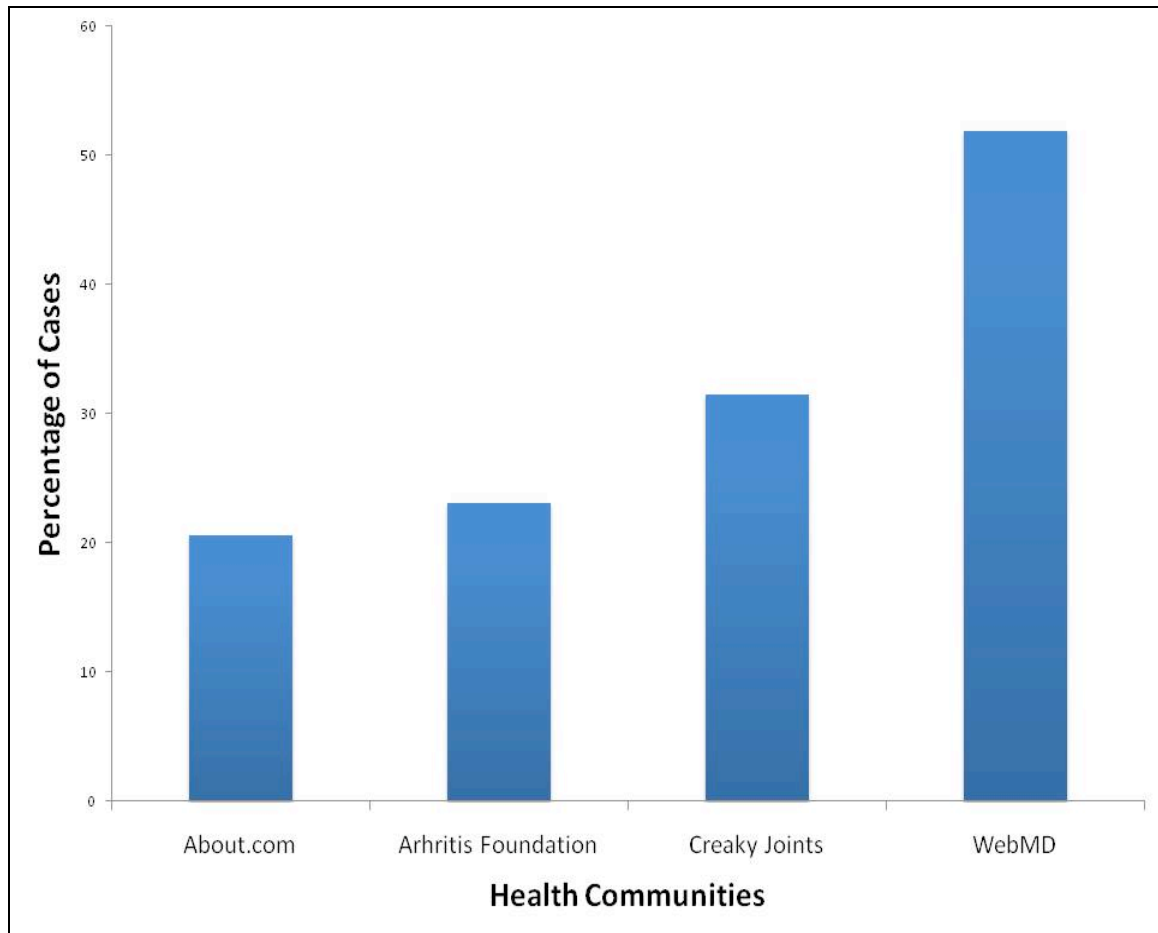


Figure 8. Percentage of cases that were coded as social support within each community.



*Figure 9.* Percentage of cases that were coded as communication within each community.

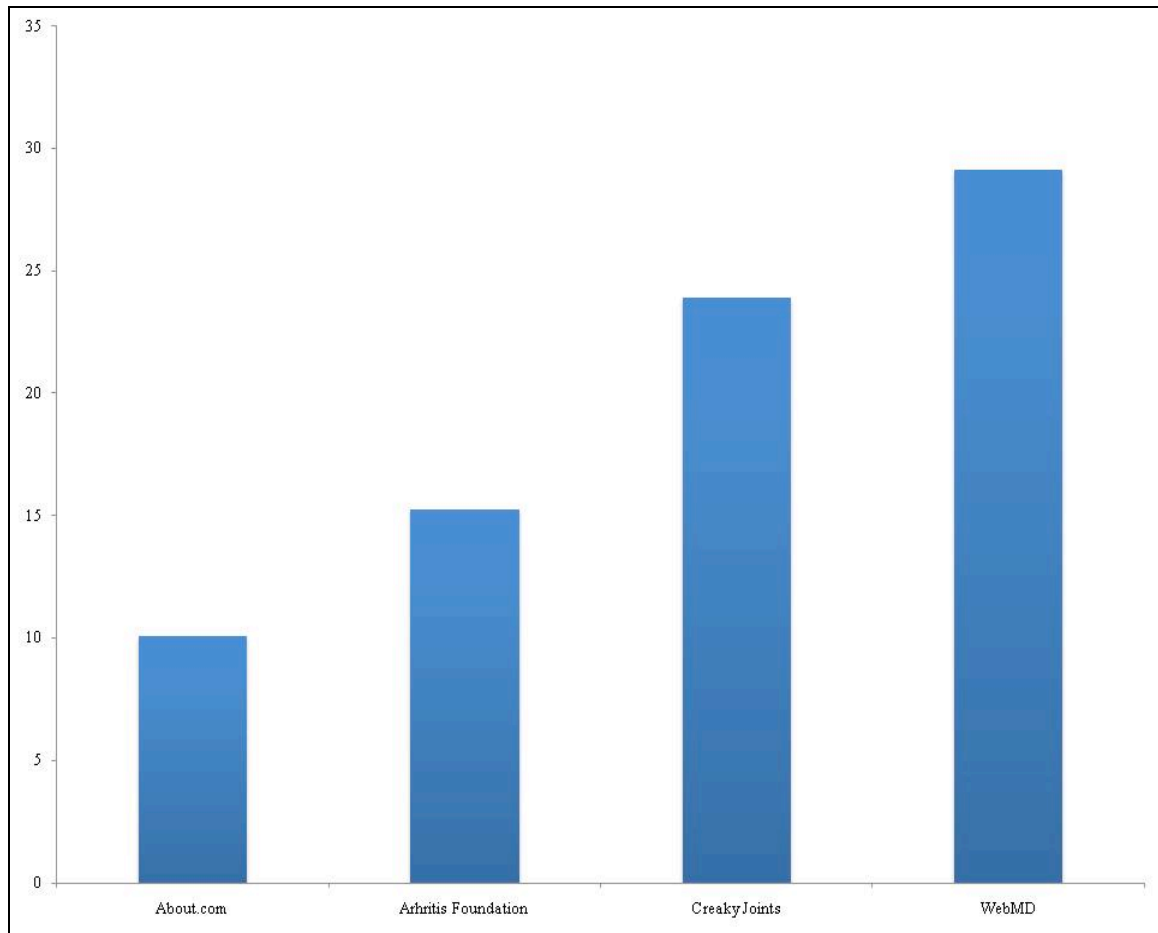
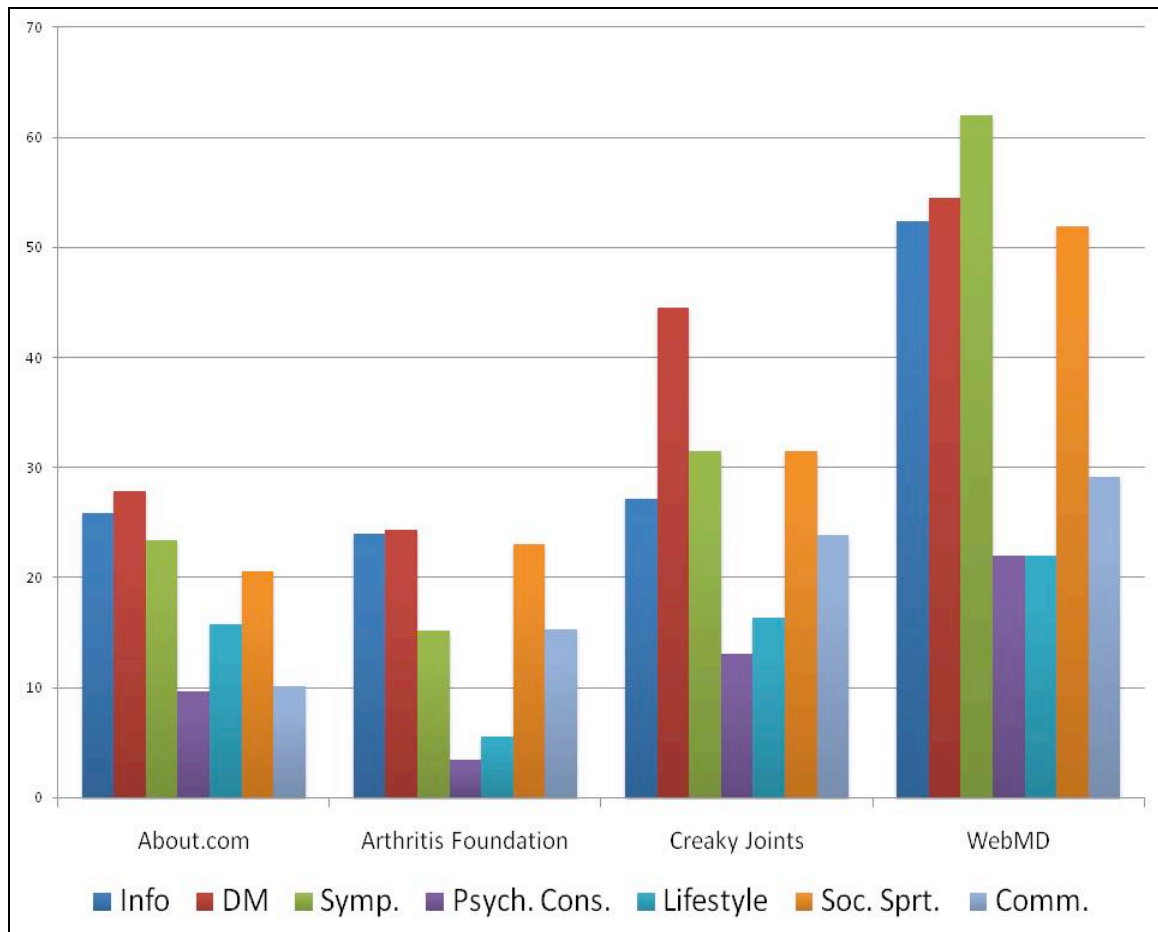


Figure 10. Percentage of cases coded.



*Figure 11.* Mean score for self-efficacy in online health communities.

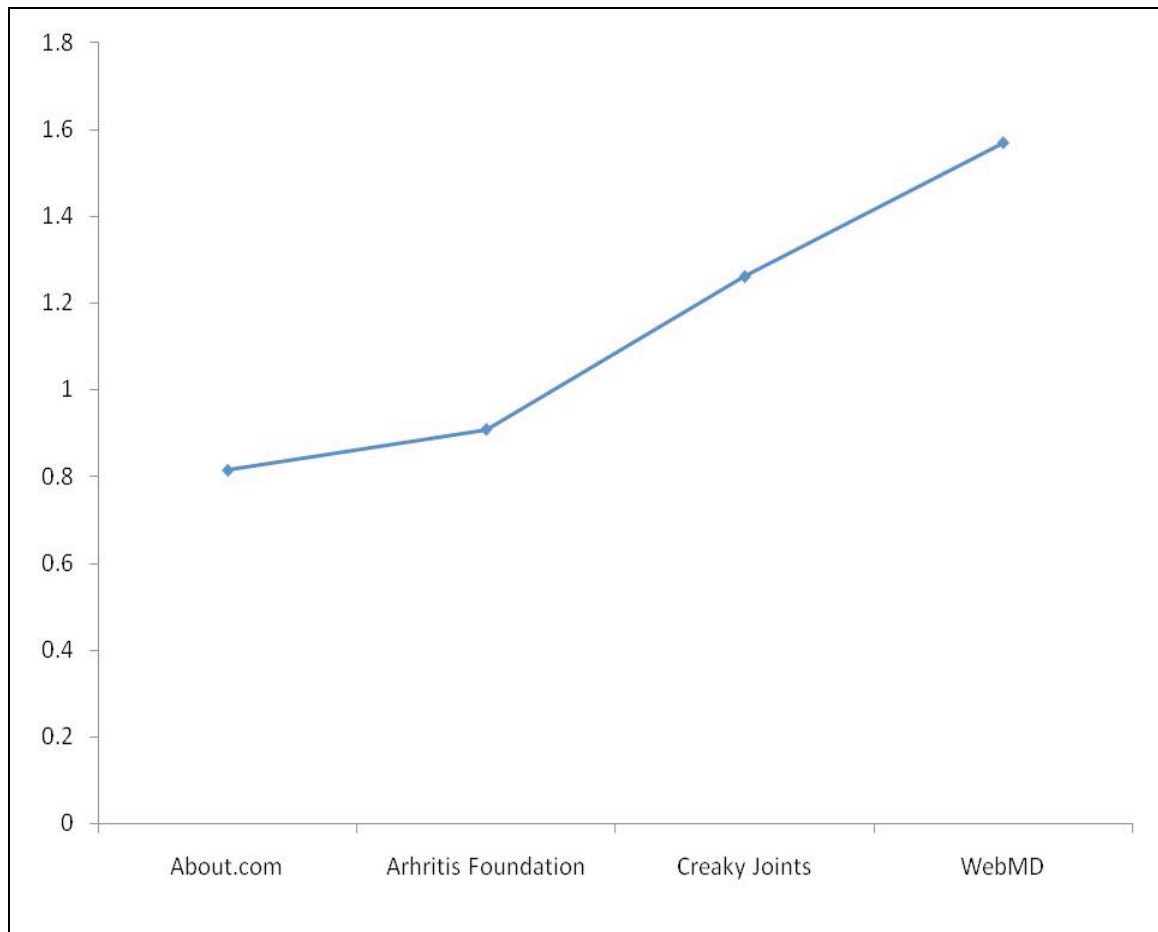
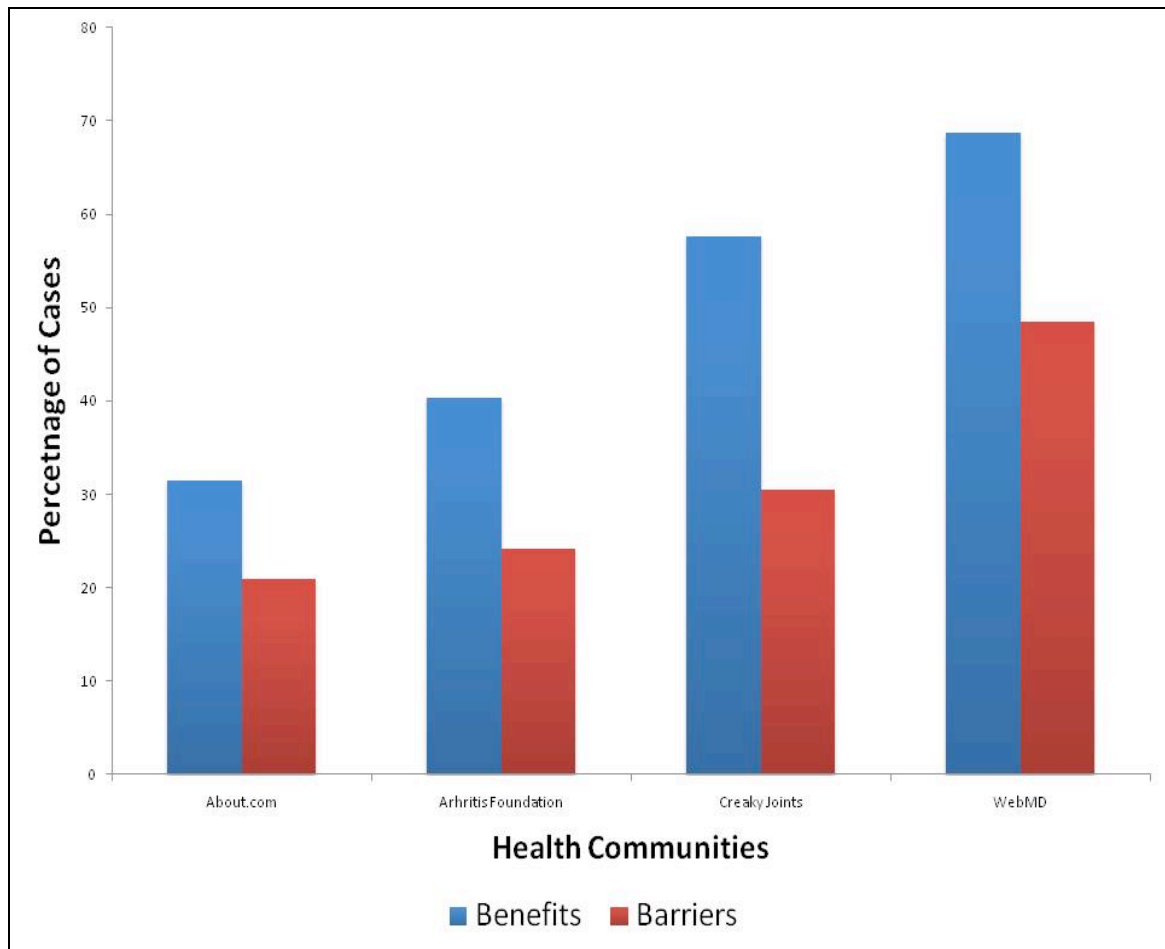


Figure 12. Percentage of cases coded as perceived benefits and perceived barriers.



## REFERENCES

- Agar, M.H. (1996). *The professional stranger: An informal introduction to ethnography*. London: Academic Press, Inc.
- Ajzen, I. (1985). From intention to action: A theory of planned behavior. In Kuhl, J. & Beckmann, J. (Eds.), *Action control: From cognition to behavior* (pp. 11-40). New York: Springer-Verlag.
- Albarracin, D., Fishbein, M., Johnson, B.T., & Muellerleile, P. (2001). Theories of reasoned action and planned behavior as models of condom use: A meta-analysis. *Psychological Bulletin*, 123, 142-161.
- Alderson, M., Starr, L., Gow, S., & Morland, J. (1999). The program for rheumatic independent self-management: A pilot evaluation. *Clinical Rheumatology*, 18, 283-292.
- Al-Shammary, N., Awan, S., Butt, K., & Yoo, J. (2007). Internet use before consultation with a health professional. *Primary Health Care*, 17(10), 18-21.
- American Medical Association Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. (1999). Health literacy: Report on the council on scientific affairs. *Journal of the American Medical Association*, 281, 552-557.
- Apgar, M. (1983). Ethnography and cognition. In R.M. Emerson (Ed.), *Contemporary field research: A collection of readings* (pp. 68-77). Prospect Heights, IL: Waveland.
- Atkinson, N.L. & Gold, R.S. (2002). The promise and challenge of eHealth interventions. *American Journal of Health Behavior*, 26(6), 494-503.
- Bagozzi, R.P., Moore, D.J., & Leone, L. (2004). Self-control and the self-regulation of dieting decisions: The role of prefactual attitudes, subjective norms, and resistance to temptation. *Basic and Applied Social Psychology*, 26(2&3), 199-213.
- Bailey, W.C., Kohler, C.L., Richards, J.M., Windsor, R.A., Brooks, C.M., Gerald, L.B., et al. (1999). Asthma self-management – do patient education programs always have an impact? *Archives of Internal Medicine*, 159, 2422-2428.
- Baker, D.W., Gazmararian, J.A., Williams, M.V., Scott, T., Parker, R.M., Green, D., Ren, J., & Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*, 92(8), 1278-1283.
- Ball, M.J. & Lillis, J. (2001). E-health: Transforming the physician/patient relationship. *International Journal of Medical Informatics*, 61, 1-10.



- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191-215.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall.
- Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist*, 44, 1175-1184.
- Bandura, A. (1994a). Self-efficacy. In Ramchaudran, V.S. (Ed.), *Encyclopedia of human behavior* (Vol. 4, pp. 71-81). New York: Academic Press.
- Bandura, A. (1994). Social cognitive theory and exercise of control over HIV infection. In DiClemente, R.J. & Peterson, J.L. (Eds.), *Preventing AIDS: Theories and methods for behavior change* (pp. 25-57). New York: Plenum Press.
- Bandura, A. (1995). Exercise of personal and collective efficacy in changing societies. In Bandura, A. (Ed.), *Self-efficacy in changing societies* (pp. 1-45). New York: Cambridge University Press.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W.H. Freeman and Company.
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, 31(2), 143-164.
- Banerjee, I. & Hsi-Shi Leong, C. (2006). Internet in the war against HIV/AIDS in Asia. In Murero, M. & Rice, R.E. (Eds.), *The Internet and health care: Theory, research and practice* (pp. 357-373). Mahwah, NJ: Lawrence Erlbaum.
- Bargh, J.A., McKenna, K.Y., & Fitzsimons, G.M. (2002). Can you see the real me? Activation and expression in the "true self" on the Internet. *Journal of Social Issues*, 58, 33-48.
- Barlow, J. & Barefoot, J. (1996). Group education for people with arthritis. *Patient Education & Counseling*, 23, 115-124.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education & Counseling*, 48(2), 177-187.
- Baym, N. (1997). Interpreting soap operas and creating community: Inside an electronic fan culture. In Kiesler, S. (Ed.), *Culture of the Internet* (pp. 103-119). Mahwah, NJ: Lawrence Erlbaum Associates.

- Benigeri, M. & Pluye, P. (2003). Shortcomings of health information on the Internet. *Health Promotion International*, 18(4), 381-386.
- Berleson, B. (1952). *Content Analysis in Communication Research*. New York: Free Press.
- Bernard, H.R. (1995). *Research methods in anthropology* (2<sup>nd</sup> ed.). London: Sage Publications.
- Bieber, M., Engelhardt, D., Furuta, R., Hiltz, S.R., Noll, J., Preece, J., Stohr, E.A., Turoff, M., & Walle, B.V.D. (2002). Towards virtual community knowledge evolution. *Journal of Management Information Systems*, 18(4), 11-35.
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of the American Medical Association*, 288(19), 2469-2475.
- Booth, M.L., Owen, N., Bauman, A., Clavisi, O., & Leslie, E. (2000). Social cognitive and perceived environment influences associated with physical activity in older Australians. *Preventative Medicine*, 31(1), 15-22.
- Boyd, D.M. & Ellison, N.B. (2008). Social network sites: Definition, history, and scholarship. *Journal of Computer-Mediated Communication*, 13(1), 210-230.
- Brady, T.J., Kruger, J., Helmick, C., Callahan, L., & Boutaugh, M. (2003). Intervention programs for arthritis and other chronic diseases. *Health Education & Behavior*, 30(1), 44-63.
- Braithwaite, D.O., Waldron, V.R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication*, 11(2), 123-151.
- Brown, S.A. & Hanis, C.L. (1995). A community-based, culturally sensitive education and group-support intervention for Mexican-Americans with NIDDM: A pilot study of efficacy. *Diabetes Education*, 21, 203-210.
- Brubaker, R.G. & Wickersham, D. (1990). Encouraging the practice of testicular self-examination: A field application of the theory of reasoned action. *Health Psychology*, 9(2), 154-163.
- Bundorf, M.K., Baker, L., Singer, S., & Wagner, T. (2004). Consumer demand for health information on the Internet. International Society of Technology Assessment in Health Care Meeting, Canmore, Atlanta.
- Burgoon, J.K., Bonito, J.A., Ramirez, Jr., A., Dunbar, N.E., Kam, K., & Fischer, J. (2002). Testing the interactivity principle: Effects of mediation, propinquity, and verbal and nonverbal modalities in interpersonal interaction. *Journal of Communication*, 52(3), 657-677.

- Bury, M. (2001). Illness narratives: Fact of fiction? *Sociology of Health & Illness*, 23(3), 263-285.
- Bury, M. (2005). *Health and illness*. Cambridge: Polity Press.
- Centers for Disease Control and Prevention. (2000). *Healthy People 2000*. Available online at <http://www.healthypeople.gov/>.
- Centers for Disease Control and Prevention. (2009). Arthritis: Intervention Programs. Available online at <http://www.cdc.gov/arthritis/interventions.htm>.
- Chaffee, S.H. & Roser, C. (1986). Involvement and the consistency of knowledge, attitudes and behaviors. *Communication Research*, 13(3), 373-399.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Clark, N.M., Becker, M.H., Janz, N.K., Lorig, K. et al. (1991). Self-management of chronic disease by older adults: A review and questions for research. *Journal of Aging and Health*, 3, 3-37.
- Clayton, H. (2003). The flat-pack patient? Creating healthier together. *Patient Education & Counseling*, 62(3), 288-290.
- Cline, R.J.W. & Haynes, K.M. (2001). Consumer health information seeking on the Internet: The state of the art. *Health Education Research*, 16(6), 671-692.
- comScore. (2007). comScore Media Matrix releases top 50 Web rankings and analysis. Available online at [http://www.comscore.com/Press\\_Events/Press\\_Releases/2007/04/Top\\_Websites\\_in\\_the\\_US/\(language\)/eng-US](http://www.comscore.com/Press_Events/Press_Releases/2007/04/Top_Websites_in_the_US/(language)/eng-US).
- Conner, M. & Norman, P. (Eds.). (2005). *Predicting health behavior: Research and practice with social cognition models* (2<sup>nd</sup> ed.). Buckingham: Open University Press.
- Corbin, J. & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass Publishers.
- Danaher, B.G., Boles, S.M., Akers, L., Gordon, J.S., & Severson, H.H. (2006). Defining participate exposure measures in Web-based health behavior change programs. *Journal of Medical Internet Research*, 8(3), e15.
- Danaher, B.G. & Seely, J.R. (2009). Methodological issues in research on Web-based behavioral interventions. *Annals of Behavioral Medicine*, 38(1), 28-39.

- Deci, E.L. & Ryan, R.M. (1985). *Intrinsic motivation and self-determination in human behavior*. New York: Plenum Press.
- Delic, D., Polasek, O., & Kern, J. (2006). Internet health information seekers in Croatia – who, what, and why? *Medical Informatics and the Internet in Medicine*, 31(4), 267-273.
- Denzin, N.K. (1997). *Interpretive ethnography: Ethnographic practices for the 21<sup>st</sup> century*. Thousand Oaks, CA: Sage.
- DeWalt, D.A., Berkman, N.D., Sheridan, S., Lohr, K.N., & Pignone, M.P. (2004). Literacy and health outcomes. *Journal of General Internal Medicine*, 19, 1228-1239.
- Dewey, M.E. (1983). Coefficients of agreement. *British Journal of Psychiatry*, 143, 487-489.
- Diaz, J.A., Griffith, R.A., Ng, J.J., Reinert, S.E., Friedmann, P.D., & Moulton, A.W. (2002). Patients' use of the Internet for medical information. *Journal of General Internal Medicine*, 17(3), 180-185.
- Dickens, C. & Creed, F. (2001). The burden of depression in patients with rheumatoid arthritis. *Rheumatology*, 40, 1327-1330.
- Dolan, G., Iredale, R., Williams, R., & Ameen, J. (2004). Consumer use of the Internet for health information: A survey of primary care patients. *International Journal of Consumer Studies*, 28(2), 147-153.
- Dubrovsky, V.J., Kiesler, S., & Sethna, B.N. (1991). The equalization phenomenon: Status effects in computer-mediated and face-to-face decision-making groups. *Human-Computer Interaction*, 6, 119-146.
- Dutta-Bergman, M.J. (2004). Health attitudes, health cognitions, and health behaviors among Internet health information seekers: Population-based survey. *Journal of Medical Internet Research*, 6(2), e15.
- Dutta-Bergman, M.J. (2006). Media use theory and Internet use for health care. In Murero, M. & Rice, R.E. (Eds.), *The Internet and health care: Theory, research, and practice* (pp. 83-103). Mahwah, NJ: Lawrence Erlbaum.
- Edelman Trust Barometer. (2008). Available online:  
[http://www.edelman.com/trust/2008/trustbarometer08\\_Final.pdf](http://www.edelman.com/trust/2008/trustbarometer08_Final.pdf).
- Elder, J.P., Ayala, G.X., & Harris, S. (1999). Theories and intervention approaches to health-behavior change in primary care. *American Journal of Preventative Medicine*, 17(4), 275-284.

- Emerson, R.M. (1983). *Contemporary field research: A collection of readings*. Prospect Heights, IL: Waveland.
- Eng, T.R. (2001). *The eHealth landscape: A terrain map of emerging information and communication technologies in health and health care*. Princeton, NJ: The Robert Wood Johnson Foundation.
- Eng, T.R. (2004). Population health technologies: Emerging innovations for the health of the public. *American Journal of Preventative Medicine*, 26(3), 237-242.
- Eng, T.R. (2005). Emerging technologies for cancer prevention and other population health challenges. *Journal of Medical Internet Research*, 7(3), e30.
- Eysenbach, G. (2000). Recent advances: Consumer health informatics. *British Medical Journal*, 320, 1713-1716.
- Eysenbach, G. & Kohler, C. (2002). How do consumers search for and appraise health information on the World Wide Web? *British Medical Journal*, 324, 573f.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support systems: Systematic review of the effects of online peer to peer interaction. *British Medical Journal*, 328(7449), 1166-1171.
- Feil, E.G., Noell, J., Lichtenstein, E., Boles, S.M., & McKay, H.G. (2003). Evaluation of an Internet-based smoking cessation program: Lessons learned from a pilot study. *Nicotine and Tobacco Research*, 5, 189-194.
- Fernback, J. (1999). There is a there there: Notes toward a definition of cybercommunity. In Jones, S. (Ed.), *Doing Internet research: Critical issues and methods for examining the Net*. Thousand Oaks, CA: Sage Publications, Inc.
- Fernback, J. & Thompson, B. (1995). Virtual communities: Abort, retry, failure? Originally presented as *Computer mediated communication and the American collectivity: The dimensions of a community within cyberspace* at the annual meeting of the International Communication Association, Albuquerque, New Mexico. Available: <http://www.well.com/user/hlr/texts/VCcivil.html>.
- Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work*, 24, 220-240.
- Fishbein, M. & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.

- Fisher, W.A., Fisher, J.D., & Rye, B.J. (1995). Understanding and promoting AIDS-preventative behavior: Insights from the theory of reasoned action. *Health Psychology, 14*(3), 255-264.
- Fox, S. (2008). The engaged e-patient population. Washington, DC: The Pew Internet and American Life Project. Available at [http://pewinternet.org/pdfs/PIP\\_Health\\_Aug08.pdf](http://pewinternet.org/pdfs/PIP_Health_Aug08.pdf).
- Frost, J.H. & Massagli, M.P. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Internet Medical Research, 10*(3), e15.
- Gabriel, S.E., Crowson, C.S., & O'Fallon, W.M. (1999). Comorbidity in arthritis. *Journal of Rheumatology, 26*(11), 2475-2479.
- Gallant, M. (2003). The influence of social support on chronic illness self-management: A review and directions for research. *Health Education & Behavior, 30*(2), 170-195.
- Garcia, A.C., Standlee, A.I., Bechkoff, J., & Cui, Y. (2009). Ethnographic approaches to the Internet and computer-mediated communication. *Journal of Contemporary Ethnography, 38*(1), 52-84.
- Garfinkel, H. (1967). *Studies in ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.
- Gazmararian, J.A., Williams, M.V., Peel, J., & Baker, D.W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling, 51*, 267-275.
- Geertz, C. (1973). Thick description: Toward an interpretive theory of culture. In Geertz, C. (Ed.), *The interpretation of cultures: Selected essays* (pp. 3-30). New York: Basic Books.
- Ghosh, C.S., Ravindran, P., Joshi, H., & Stearns, S.C. (1998). Reductions in hospital use from self-management training for chronic asthmatics. *Social Science Medicine, 46*, 1087-1093.
- Glanz, K., Rimer, B.K., & Lewis, F.M. (2002). *Health behavior and health education, theory, research, and practice*. San Francisco: Wiley & Sons.
- Glasgow, R.E., Toobert, D.J., Hampson, S.E., Brown, J.E., Lewinsohn, P.M., & Donnelly, J. (1992). Improving self-care among older patients with Type II diabetes: The "Sixty Something..." study. *Patient Education & Counseling, 19*, 61-74.
- Goeppinger, J., Lorig, K., Ritter, P., Mutatkar, S., Villa, F., & Gizlice, Z. (2009). Mail-delivered arthritis self-management tool kit: A randomized trial and longitudinal follow up. *Arthritis & Rheumatism, 61*(7), 867-875.

- Gold, B.C., Burke, S., Pintauro, S., Buzzell, P., & Harvey-Berino, J. (2007). Weight loss on the Web: A pilot study comparing a structured behavioral intervention to a commercial program. *Obesity, 15*(1), 155-164.
- Goldner, M. (2006). Using the Internet and email for health purposes: The impact of health status. *Social Science Quarterly, 87*(3), 690-710.
- Goldsmith, J. (2000). How will the Internet change our health system? *Health Affairs, 19*(1), 148-156.
- Greenberg, D. (2001). A critical look at health literacy. *Adult Basic Education, 11*(2), 67-79.
- Hagel, J. & Armstrong, A. (1997). *Net Gain: Expanding markets through virtual communities*. Massachusetts: Harvard Business School Press.
- Hammersley, P. & Atkinson, M. (2007). *Ethnography: principles in practice*. New York: Taylor & Francis.
- Han, H.R. & Belcher, A.E. (2001). Computer-mediated support group among parents of children with cancer – an exploratory study. *Computers, Informatics, Nursing, 19*(1), 27-33.
- Hardeman, W., Johnston, M., Johnston, D., Bonetti, D., Wareham, N.J., & Kinmonth, A.L. (2002). Application of the theory of planned behavior-change interventions: A systematic review. *Psychology and Health, 17*, 123-158.
- Henwood, F., Wyatt, S., Hart, A., & Smith, J. (2004). Ignorance is bliss sometimes: Constraints on the emergence of the informed patient in the changing landscapes of health information. In Seale, C. (Ed.), *Health and the media* (pp. 74-91). Oxford, UK: Blackwell Publishing.
- Herring, S.C. (1996). Two variants of an electronic message schema. In Herring, S. (Ed.), *Computer-mediated communication: Linguistic, social and cross-cultural perspectives* (pp. 81-106). Philadelphia: John Benjamins Publishing Company.
- Herring, S.C. (2004). Computer-mediated discourse analysis: An approach to researching online behavior. In S.A. Barab & R. Kling (Eds.), *Designing for virtual communities in the service of learning* (pp. 338-376). Cambridge: Cambridge University Press.
- Hillery, Jr., G.A. (1955). Definitions of community: Areas of agreement. *Rural Sociology, 20*(4), 111f.
- Hiltz, S.R. (1985). *Online communities: A case study of the office of the future*. Norwood, NJ: Ablex Publishing Corporation.
- Hine, C. (2000). *Virtual ethnography*. Thousand Oaks, CA: Sage Publications, Inc.

- Holman, H. & Lorig, K. (2004). Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports*, 119, 239-244.
- Iakovidis, I., Wilson, P., & Healy, J.C. (2004). *E-health: Current situation and examples of implemented and beneficial e-health applications*. Amsterdam: IOS Press.
- Jankowski, N.W. & Wester, F. (1991). The qualitative tradition in social science inquiry: Contributions to mass communication research. In Jensen, K.B. & Jankowski, N.W. (Eds.), *A handbook of qualitative methodologies for mass communication research* (pp. 44-74). London: Routledge.
- Jerant, A.F., von Friederichs-Fitzwater, M.M., & Moore, M. (2005). Patients' perceived barriers to active self-management of chronic conditions. *Patient Education and Counseling*, 57, 300-307.
- Jones, S.G. (1995). *CyberSociety: Computer-mediated communication and the community*. Thousand Oaks, CA: Sage Publications, Inc.
- Jones, Q. (1997). Virtual-communities, virtual settlements & cyber-archeology: A theoretical outline. *Journal of Computer-Mediated Communication*, 3(3).
- Jones, F.R. (2003). Perspectives on the expert patient. Presentations from a seminar held at the Royal Pharmaceutical Society of Great Britain, May 18, 2003. Available online at <http://www.rpsgb.org.uk/pdfs/exptpatsemrept.pdf>.
- Kalichman, S.C., Benotsch, E.G., Weinhardt, L., Austin, J., & Luke, W. (2002). Internet use among people living with HIV/AIDS: Association of health information, health behavior, and health status. *AIDS Education and Prevention*, 14(1), 51-61.
- Kalichman, S.C., Benotsch, E., Weinhardt, L., Austin, J., Luke, W., & Cherry, C. (2003). Health-related Internet use, coping, social support, and health indicators in people living with HIV/AIDS: Preliminary results from a community survey. *Health Psychology*, 22, 111-116.
- Kalichman, S.C., Weinhardt, L., Benotsch, E., DiFonzo, K., Luke, W., & Austin, J. (2000). Internet access and Internet use for health information among people living with HIV/AIDS. *Patient Education and Counseling*, 46(2), 109-116.
- Katz, P.P. & Yelin, E.H. (2001). Activity loss and the onset of depressive symptoms: do some activities matter more than others? *Arthritis & Rheumatism*, 44, 1194-1202.
- Kiesler, S., Siegel, J., & McGuire, T.W. (1984). Social psychological aspects of computer-mediated communication. *American Psychologist*, 39, 1123-1134.



- Kiesler, S., Zubrow, D., Moses, A., M., & Geller, V. (1985). Affect in computer-mediated communication: An experiment in synchronous terminal-to-terminal discussion. *Human-Computer Interaction, 1*, 77-104.
- Korenman, J. & Wyatt, N. (1996). Group dynamics in an email forum. In Herring, S. (Ed.), *Computer-mediated communication: Linguistic, social and cross-cultural perspectives* (pp. 225-242). Philadelphia: John Benjamins Publishing Company.
- Korp, P. (2006). Health on the Internet: Implications for health promotion. *Health Education Research, 21*(1), 78-86.
- Kotses, H., Stout, C., McConnaughy, K., Winder, J.A., & Creer, T.L. (1996). Evaluation of individualized asthma self-management programs. *Journal of Asthma, 33*(2), 113-118.
- Kozinets, R.V. (2002). The field behind the screen: Using Netnography for marketing research in online communities. *Journal of Marketing Research, 39*(1), 61-72.
- Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: Taking action to create order. *Journal of Clinical Nursing, 13*, 259-267.
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy. Washington, DC: National Center for Education Statistics, US Department of Education.
- Lave, J. & Wenger, E. (1991). *Situated learning*. Cambridge: University of Cambridge Press.
- Lefebvre, C., Tada, Y., Hilfiker, S., & Baur, C. (2010). The assessment of user engagement with eHealth content: The eHealth Engagement Scale. *Journal of Computer-Mediated Communication, 15*(4), 666-681.
- Lewis, T. (2006). Seeking health information on the Internet: Lifestyle choice of bad attack of cyberchondria? *Media, Culture, & Society, 28*(4), 521-539.
- Lieberman, M.A. & Goldstein, B.A. (2005). Self help online: An outcome evaluation of breast cancer bulletin boards. *Journal of Health Psychology, 10*(6), 855-862.
- Lorig, K. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care, 37*(1), 5-14.
- Lorig, K. & Holman, H. (2003). Self-management education: History, definition, outcome, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7.
- Lorig, K., Gonzalez, V.M., & Ritter, P. (1999). Community-based Spanish language arthritis education program: A randomized trial. *Medical Care, 37*, 957-963.

- Lorig, K.R., Mazonson, P.D., Holman, H.R. (2005). Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis & Rheumatism*, 36(4), 439-446.
- Lorig, K., Lubeck, D., Kraines, R., Seleznick, M., & Holman, H. (1985). Outcomes of self-help education for patients with arthritis. *Arthritis & Rheumatism*, 28(6), 680-685.
- Lorig, K., Ritter, P.L., Laurent, D.D., & Plant, K. (2006). Internet-based chronic disease self-management: A randomized trial. *Medical Care*, 44(11), 964-971.
- Lorig, K., Ritter, P.L., Laurent, D.D., & Plant, K. (2008). The Internet-based arthritis self-management program: A one-year randomized trial for patients with arthritis or fibromyalgia. *Arthritis & Rheumatism*, 59(7), 1009-1017.
- Lorig, K., Ritter, P., Stewart, A., Sobel, D., William Brown, B. Jr., Bandura, A., Gonzalez, V., Laurent, D., & Holman, H. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care*, 39(11), 1217-1233.
- Lorig, K., Sobel, D., Ritter, P., Laurent, D., & Hobbs, M. (2001). Effect on a self-management program on patients with chronic disease. *Effective Clinical Practice*, 4(6), 256-262.
- Lorig, K., Sobel, D., Stewart, A., Brown, Jr., B., Bandura, A., Ritter, P., Gonzalez, V., Laurent, D., & Holman, H. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37(1), 5-14.
- Lynch, M. & Peyrot, M. (1992). Introduction: A reader's guide to ethnomethodology. *Qualitative Sociology*, 15(2), 113-122.
- Maloney-Krichmar, D. & Preece, J. (2005). A multi-level analysis of sociability, usability, community dynamics in an online health community. *Transactions on Computer Human Interaction*, 12(2), 201-232.
- Marks, R. & Allegrante, J.P. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: Implications for health education practice. *Health Promotion Practice*, 6(2), 148-156.
- McKenna, K.Y., Green, A.S., & Gleason, M.E. (2002). Relationship formation on the Internet: What's the big attraction? *Journal of Social Issues*, 58, 9-31.
- McLelland, M.J. (2002). Virtual ethnography: Using the Internet to study gay culture in Japan. *Sexualities*, 5(4), 387-406.

- McMillan, D.W. & Chavis, D.M. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, 14(1), 6-23.
- Metz, J.M. (1992). Computer-mediated communication: Perceptions of a new context. Paper presented at the Speech Communication Association Annual Conference, Chicago, IL.
- Miller, S.M., Shoda, Y., & Hurley, K. (1996). Applying cognitive-social theory to health protective behavior: Breast self-examination in cancer screening. *Psychological Bulletin*, 119(1), 70-94.
- Morahan-Martin, J.M. (2004). How Internet users find, evaluate, and use online health information: A cross-cultural view. *Cyberpsychology & Behavior*, 7(5), 497-510.
- Muniz, Jr., A.M. & O'Guinn, T.C. (2001). Brand community. *Journal of Consumer Research*, 27(4), 412-432.
- Munoz, R.F., Lenert, L.L., Delucchi, K., Stoddard, J., Perez, J.E., Penilla, C., & Perez-Stable, E.J. (2006). Toward evidence-based Internet interventions: A Spanish/English Web site for international smoking cessation trials. *Nicotine & Tobacco Research*, 8(1), 77-87.
- Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., White, M., Zapert, K., & Turner, R. (2003). The impact of health information on the Internet on the physician-patient relationship. *Archives of Internal Medicine*, 163(14), 1727-1734.
- Nardi, B. (1997). The use of ethnographic methods in design and evaluation. In Helander, M.G., Landauer, T.K., & Prabhu, P. (Eds.), *Handbook of human-computer interaction* (2<sup>nd</sup> ed.). Amsterdam, Netherlands: Elsevier Science B.V.
- National Center for Education Statistics. (2003). *National Assessment of Adult Literacy: Key findings*. Washington, DC: U.S. Department of Education.
- National Institutes of Health. (2010). Clear communication: An NIH health literacy initiative. Available online at <http://www.nih.gov/clearcommunication/>.
- National Library of Medicine. (2004). Understanding health literacy and its barriers. Available online at <http://www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html#top>.
- Neal, L., Lindgaard, G., Oakley, K., Hansen, D., Kogan, S., Leimeister, J.M., & Selker, T. (2006). Online health communities. Presentation at the Human Factors in Computing Systems Conference, Chicago.
- Neilsen-Bohlman, L., Panzer, A.M., & Kindig, D.A. (2004). *Health literacy: A prescription to end confusion*. Washington, DC: National Academies Press.

- Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *The Lancet*, 364, 1523-1537.
- Norman, P., Connor, M., & Bell, R. (1999). The theory of planned behavior and smoking cessation. *Health Psychology*, 18(1), 89-94.
- Norman, C.D., & Skinner, H.A. (2006). eHealth literacy: Essential skills for consumer health in a networked world. *Journal of Medical Internet Research*, 8(2), e9.
- Norris, S., Nichols, P., Caspersen, C., Glasgow, R., Engelgau, M., Jack, L. Jr., Snyder, S., Carande-Kulis, V., Isham, G., & Garfield, S. (2002). Increasing diabetes self-management education in community settings: A systematic review. *American Journal of Preventive Medicine*, 22(4), 39-66.
- Nour, K., Laforest, S., Gauvin, L., & Gignac, M. (2006). Behavior change following a self-management intervention for housebound older adults with arthritis: An experimental study. *International Journal of Behavioral Nutrition and Physical Activity*, 3(12).
- Nutbeam, D. (1998). Health promotion glossary. *Health Promotion International*, 13, 349-364.
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21<sup>st</sup> century. *Health Promotion International*, 15, 259-267.
- Oenema, A., Brug, J., & Lechner, L. (2001). Web-based tailored nutrition education: Results of a randomized controlled trial. *Health Education Research*, 16(6), 647-660.
- Paasche-Orlow, M.K., Gazmararian, J.A., Nielsen-Bohlman, L.T., & Rudd, R.R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20(2), 175-184.
- Paasche-Orlow, M.K. & Wolf, M.S. (2007). The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior*, 31, 19-26.
- Parker, J.C., Smarr, K., Slaughter, J.R., et al. (2003). Management of depression in rheumatoid arthritis: A combined pharmacologic and cognitive-behavioral approach. *Arthritis & Rheumatism*, 49, 766-777.
- Perkin, C. & Murphy, E. (2006). Identifying and measuring individual engagement in critical thinking in online discussions: An exploratory case study. *Educational Technology & Society*, 9(1), 298-307.
- Pew Internet & American Life Project. (2010). See: <http://pewresearch.org/pubs/1767/mobile-phone-search-health-medical-information>.

- Pecchioni, L.L. & Sparks, L. (2007). Health information sources of individuals with cancer and their family members. *Health Communication, 21*(2), 143-151.
- Pichert, J.W., Synder, C.M., Kinzer, C.K., & Boswell, E.J. (1994). Problem solving anchored instruction about sick days for adolescents with diabetes. *Patient Education & Counseling, 23*, 115-124.
- Pignone, M., DeWalt, D.A., Sheridan, S., Berkman, N., & Lohr, J.N. (2005). Intervention to improve health outcomes for patients with low literacy: A systematic review. *Journal of General Internal Medicine, 20*(2), 185-193.
- Plant, R. (2004). Online communities. *Technology in Society, 26*(1), 51-65.
- Preece, J. (2001). Sociability and usability: Twenty years of chatting online. *Behavioral Information Technology, 20*(5), 347-356.
- Preece, J. & Maloney-Krichmar, D. (2005). Online communities: Design, theory, and practice. *Journal of Computer-Mediated Communication, 10*(4), article 1.
- Preece, J., Maloney-Krichmar, D., & Abras, C. (2003). History of emergence of online communities. In Wellman, B. (Ed.), *Encyclopedia of community*. Barrington, MA: Berkshire Publishing Group.
- Preece, J., Nannecke, B., & Andrews, D. (2004). The top five reasons for lurking: Improving community experiences for everyone. *Computers in Human Behavior, 20*(2), 201-223.
- Prentice-Dunn, S. & Rogers, R.W. (1986). Protection motivation theory and preventive health: Beyond the Health Belief Model. *Health Education Research, 1*(3), 153-161.
- Prochaska, J.J., Zabinski, M.F., Calfas, K.J., Sallis, J.F., & Patrick, K. (2000). PACE+: Interactive communication technology for behavior change in clinical settings. *American Journal of Preventative Medicine, 19*(2), 127-131.
- Quan-Haase, A., Wellman, B., Witte, J., & Hampton, K. (2002). Capitalizing on the Net: Social contact, civic engagement, and sense of community. In Wellman, B. & Haythornthwaite, C. (Eds.), *The Internet in everyday life* (pp. 291-234). Malden, MA: Blackwell Publishers, Ltd.
- Raines, L. (2005). The average American Internet user is not sure what podcasting is, what an RSS feed does, or what the term "phishing" means. *Pew Internet Project Memo*, <http://pewinternet.org>.
- Ratzan, S.C. (2001). Health literacy: Communication for the public good. *Health Promotion International, 16*(2), 207-214.

- Rheingold, H. (1993). *The virtual community: Homesteading on the electronic frontier*. Reading, MA: Addison-Wesley.
- Rice, R.E. & Love, G. (1987). Electronic emotion: Socioemotional content in a computer-mediated communication network. *Communication Research*, 14, 85-108.
- Rodgers, S. & Chen, Q. (2005). Internet community group participation: Psychosocial benefits for women with breast cancer. *Journal of Computer-Mediated Communication*, 10(4), article 5. Available from <http://jcmc.indiana.edu/vol10/issue4/rodgers.html>.
- Romm, C., Pliskin, N., & Clarke, R. (1997). Virtual communities and society: Toward an integrative three phase model. *International Journal of Information Management*, 17(4), 260-271.
- Rosenstock, I.M., Strecher, V.J., & Becker, M.H. (1988). Social learning theory and the health belief model. *Health Education & Behavior*, 15(2), 175-183.
- Sade-Beck, L. (2004). Internet ethnography: Online and offline. *International Journal of Qualitative Methods*, 3(2).
- Salmon, C.T. (1986). Perspectives on involvement in consumer and communication research. In Dervin, B. & Voigt, M.J. (Eds.), *Progress in communication sciences* (pp. 243-268). Norwood, NJ: Ablex.
- Schifter, D.E. & Ajzen, I. (1985). Intention, perceived control, and weight loss: An application of the theory of planned behavior. *Journal of Personality and Social Psychology*, 49(3), 843-851.
- Schuler, D. (1996). *New community networks: Wired for change*. Reading, MA: ACM Press & Addison-Wesley Publishing Co.
- Scott, W. (1955). Reliability of content analysis: The case of nominal scale coding. *Public Opinion Quarterly*, 19(3), 321-325.
- Sheeran, P. & Orbell, S. (2000). Using implementation intentions to increase attendance for cervical cancer screening. *Health Psychology*, 19(3), 283-289.
- Silence, E., Briggs, P., Harris, P.R., & Fishwick, L. (2007). How do patients evaluate and make use of online health information? *Social Science & Medicine*, 64(9), 1853-1862.
- Silver, D. (1999). Localizing the global village: Lessons from the Blacksburg Electronic Village. In Browne, R.B. & Fishwick, M.W. (Eds.), *The global village: Dead or alive?* (pp. 79-92). Bowling Green, OH: Popular Press.

- Solomon, D.H., Warsi, A., Brown-Stenson, T., Farrell, M., Gauthier, S., Mikels, D., & Lee, T.H. (2002). Does self-management education benefit all populations with arthritis? A randomized controlled trial in a primary care physician network. *Journal of Rheumatology*, 29(2), 362-368.
- Sproull, L. & Kiesler, S. (1991). *Connections: New ways of working in the networked organization*. Cambridge, MA: MIT Press.
- Stenstrom, C. & Minor, M.A. (2003). Evidence for the benefit of aerobic and strengthening exercise in rheumatoid arthritis. *Arthritis Care & Research*, 49(3), 428-434.
- Stinson, J.N., McGrath, P.J., Hodnett, E.D., Feldman, B.M., Duffy, C.M., Huber, A.M., Tucker, L.B., Hetherington, C.R., Tse, S., Spiegel, L.R., Campillo, S., Gill, N.K., & White, M.E. (2010). An Internet-based self-management program with telephone support for adolescents with arthritis: A pilot randomized controlled trial. *Journal of Rheumatology*, 37(9), 1944-1952.
- Strauss, A. & Corbin, J. (1997). *Grounded theory in practice*. Thousand Oaks, CA: Sage Publications.
- Strecher, V.J., Seijts, G.H., Kok, G.J., Latham, G.P., Glasgow, R., DeVellis, B., Meertens, R.M., Bulger, D.W. (1995). Goal setting as a strategy for health behavior change. *Health Education & Behavior*, 22(2), 190-200.
- Summers, K. & Summers, M. (2004). Making the Web friendlier for lower-literacy users. Intercom, June 19-21. Available from [www.stc.org/intercom/pdfs/2004/200406\\_19-23.pdf](http://www.stc.org/intercom/pdfs/2004/200406_19-23.pdf).
- Tang, E. & Lee, W. (2006). Singapore Internet users' health information search: Motivation, perception of information sources, and self-efficacy. In Murano, M. & Rice, R.E. (Eds.), *The Internet and health care: Theory, research, and practice* (pp. 107-126). Mahwah, NJ: Lawrence Erlbaum.
- Tate, D.F., Jackvony, E.H., & Wing, R.R. (2003). Effects of Internet behavioral counseling on weight loss in adults at risk for Type 2 diabetes. *Journal of the American Medical Association*, 289, 1833-1836.
- Tate, D.F., Wing, R.R., & Winett, R.A. (2001). Using Internet technology to deliver a behavioral weight-loss program. *Journal of the American Medical Association*, 285, 1172-1177.
- Taylor, T.J. & Cameron, C. (1987). *Analyzing conversation*. Oxford: Pergammon.
- Tedesco, L.A., Keffer, M.A., & Fleck-Kandath, C. (1991). Self-efficacy, reasoned action, and oral health behavior reports: A social cognitive approach to compliance. *Journal of Behavioral Medicine*, 14(4), 341-355.

- Theis, K., Helmick, C., & Hootman, J. (2007). Arthritis burden and impact are greater among U.S. women than men: Intervention opportunities. *Journal of Women's Health, 16*(4), 441-453.
- Tidwell, L.C. & Walther, J.B. (2002). Computer-mediated communication effects on disclosure, impressions, and interpersonal evaluations: Getting to know one another a bit at a time. *Human Communication Research, 28*(3), 317-348.
- van Everdingen, A., Jacobs, J.W.G., Siewertsz van Reesema, D.R., & Bijlsma, J.W.J. (2002). Low-dose Prednisone therapy for patients with early active rheumatoid arthritis: Clinical efficacy, disease-modifying properties, and side effects: A randomized, double-blind, placebo-controlled clinical trial. *Annals of Internal Medicine, 136*(1), 1-12.
- van den Berg, M.H., Runday, H.K., Peeters, A.J., Voogt-van der Harst, E.M., Munneke, M., Breedveld, F.C., & Vliet Vlieland, T.P.M. (2007). Engagement and satisfaction with an Internet-based physical activity intervention in patients with rheumatoid arthritis. *Rheumatology, 46*(3), 545-552.
- Walther, J.B. (1992). Interpersonal effects in computer-mediated interaction: A relational perspective. *Communication Research, 19*, 52-90.
- Walther, J.B. (1995). Relational aspects of computer-mediated communication: Experimental behaviors over time. *Organization Science, 6*, 186-203.
- Walther, J.B. (1999). Selective self-presentation in computer-mediated communication. The National Communication Association Conference, November 4-7, Chicago.
- Walther, J.B. & Boyd, S. (2002). Attraction to computer-mediated social support. In Lin, C.A. & Atkin, D. (Eds.), *Communication technology and society: Audience adoption and uses* (pp. 153-188). Cresskill, NJ: Hampton Press.
- Walther, J.B., Loh, T., & Granka, L. (2005). Let me count the ways: The interchange of verbal and nonverbal cues in computer-mediated and face-to-face affinity. *Journal of Language and Social Psychology, 24*(1), 36-65.
- Wantland, D.J., Portillo, C.J., Holzemer, W.L., Slaughter, R., & McGhee, E.M. (2004). The effectiveness of Web-based vs. non-Web-based interventions: A meta-analysis of behavioral change outcomes. *Journal of Internet Medical Research, 6*(4), e40.
- Watson, R. (2009). *Analyzing practical and professional texts: A naturalistic approach*. Burlington, VT: Ashgate Publishing Company.
- White, M. & Dorman, S.M. (2000). Online support for caregivers: Analysis of an Internet Alzheimer mailgroup. *Computers, Informatics, Nursing, 18*(4), 168-176.



- White, M. & Dorman, S.M. (2001). Receiving social support online: Implications for health education. *Health Education Research*, 16(6), 693-707.
- Weisband, S. & Atwater, L. (1999). Evaluating self and others in electronic and face-to-face groups. *Journal of Applied Psychology*, 84, 632-639.
- Williamson, K. (2005). Where one size does not fit all: Understanding the needs of potential users of a portal to breast cancer knowledge online. *Journal of Health Communication*, 10, 567-580.
- Wilson, S.R., Latini, D., Starr, N.J., Fish, L., Loes, L.M., Page, A., et al. (1996). Education of parents of infants and very young children with asthma: A development evaluation of the Wee Wheezers programme. *Journal of Asthma*, 33, 239-254.
- Willis, E., Wang, Y., & Rodgers, S. (in press). Online health communities and health literacy: Applying a framework for understanding domains of health literacy. In Smedberg, A. (Ed.), *E-health communities and online self-help groups: Applications and usage*. Hershey, PA: IGA Global.
- Wimmer, R.D., & Dominick, J.R. (1983). *Mass media research, an introduction*. Belmont, CA: Wadsworth, Inc.
- Woodruff, S.I., Edwards, C.C., Conway, T.L., & Elliott, S.P. (2001). Pilot test of an Internet virtual world chat room for rural teen smokers. *Journal of Adolescent Health*, 29(4), 239-243.
- Wright, K. (1999). Computer-mediated support groups: An examination of relationships among social support, perceived stress, and coping strategies. *Communication Quarterly*, 47, 402-414.
- Wright, K. (2000). Computer-mediated social support, older adults and coping. *Journal of Communication*, 50(3), 100-118.
- Wright, K. (2002). Social support within an online cancer community: An assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. *Journal of Applied Communication Research*, 30(3), 195-209.
- Zarcadoolas, C., Blanco, M., Boyer, J.F., & Pleasant, A. (2002). Unweaving the Web: An exploratory study of low-literate adults' navigation skills on the World Wide Web. *Journal of Health Communication*, 7(4), 309-324.
- Zarcadoolas, C., Pleasant, A., & Greer, D.S. (2005). Understanding health literacy: An expanded model. *Health Promotion International*, 20(2), 195-203.

Zarcadoolas, C., Pleasant, A., & Greer, D.S. (2006). *Advancing health literacy: A framework for understanding and action*. San Francisco, CA: Jossey-Bass.

## **CHAPTER XII**

### **VITA**

Erin Willis was born in Durango, Colorado in 1980 but grew up in Branson, Missouri. She attended the University of Missouri for her undergraduate work where she studied Marketing. Upon graduation, she moved to Chicago to work at Cushman/Amberg Communications in public relations. Later, Erin was offered an opportunity to open a city/regional magazine in Branson, so she moved home. After a few issues of Vue magazine, she decided that she wanted to return to school for a graduate degree in Journalism at the Missouri School of Journalism. While earning her master's degree, Erin worked as a research assistant at the Missouri Arthritis Rehabilitation Research and Training Center, a federally-funded grant project at the University of Missouri. This job sparked her interest in health communication research and eventually convinced her to go on and earn a doctorate in the field.

Erin's research focuses on health communication, new media and strategic communication. Her research focuses on chronic disease self-management and health literacy. She has accepted an assistant professor position at the University of Memphis where she will teach public relations to both undergraduate and graduate students.