

Running Head: CHRONIC ILLNESS AND ONLINE COMMUNITIES

Chronic illness and online communities: a positive partnering

Alyssa Rosenzweig

University of Pennsylvania

Abstract

We now live in a world where diagnosis of a chronic illness is not assumed to be a death sentence. Medical and technological progress has resulted in longer lives and more advanced treatment techniques. After the initial diagnosis and sharp learning curve that is expected with such a drastic lifestyle and behavior change, the majority of the person's time and energy will be spent on acquiring more advanced treatment and coping techniques. This specialized "information need" goes beyond the knowledge in most books, reference websites and medical professionals' training. By their very nature, online communities and other social technologies provide an appropriate means to positively address this need. This paper will examine the traits and needs shared generally among chronic illness populations and the benefits of their partnership with online communities in this new, interdisciplinary research area.

Chronic illness and online communities: a positive partnering

We now live in a world where diagnosis of a chronic illness is not assumed to be a death sentence. Medical and technological progress has resulted in longer lives and more advanced treatment techniques; chronic illness patients can now expect to live lives nearly as long as - or longer - than their healthy counterparts. Beginning on the day of diagnosis, the patient must adapt to his or her new living circumstances and change his or her health behavior practices. On top of learning the basic mechanics of the illness and its treatment, new health information needs to be monitored and priorities must be shifted. It is a life-dependent responsibility that the patient will have to cope with for the rest of his or her life, barring the possibility of a cure in his or her lifetime. These life changes are experienced by individuals with various chronic illnesses, including cancer, diabetes, hemophilia, AIDS/HIV, severe allergies, asthma, and epilepsy. Despite different symptom presentations and treatment regimens, the challenges faced by these populations are generally quite similar.

Regardless of the specific chronic illness, the initial diagnosis phase is difficult. There is an overwhelming amount of information to learn about human biology, treatment methods, health outcomes and risks, and other standard medical treatment and diagnosis practices. Frequently this is taught in a “crash course” style with a physician or other medical staff, supplemented with books, websites and other educational materials to study at home. This type of information is widely available and easily accessible—especially on the Internet where an increasing number of people are conducting personal health research (Fox *et al.*, 2000; Kerr, 2005). The focus tends to be centered on the theoretical (*e.g.* how the body is malfunctioning) and quantifiable (*e.g.* blood pressure, cell counts, body-mass index) measures and skills, since those are the most salient and conventional variables monitored in medicine.

Fear of experiencing negative symptoms or worse, long-term health outcomes (*e.g.* complications, premature death) motivates the chronic illness patient to quickly learn the treatment protocols and as much information as one can about the illness. Mastery and immediate application of the skills is imperative, as each moment of inattention to the illness can have a direct effect on how one feels and performs in the present and in the future. The patient learns the serious relationship between his or her actions and outcome health status—almost literally in a “do or die” sense. By necessity, it is a sharp learning curve. With time, the standard treatment behaviors are internalized and become second-nature. Ultimately, though, the information provided by medical professionals and general information resources becomes less useful to the chronic illness patient and additional resources must be discovered, as the patient works to further refine their own care.

Given the long-term nature of chronic illness, coping strategies become more important to the patient than basic information about the illness or concepts of treatment. However, the focus of the clinical-setting education during the initial diagnosis and follow-up outpatient visits is not on emotional or psychological components of the illness. The chronic illness curriculum may state that feelings such as denial, anger, confusion or depression are likely to occur over the patient’s lifetime, but this is not the same thing as experiencing the complicated emotions associated with such a long-term condition. What it feels like to have a chronic illness and its inescapable, daily coping is not a straight-forward concept that can be taught very easily. Psychological and emotional coping needs are a murky cloud of unknowns to most medical professionals, so it is less likely to be a major concern—especially in relation to the immediate need of learning illness-management skills. To the defense of medical professionals, counseling

and extensive discussion of the mental health consequences of a chronic illness are outside their formal training, so a referral to a professional is common.

Additionally, outside of basic medical knowledge of the chronic illness and its treatment, most of the information and resources traditionally available to patients does not discuss how truly complicated it is to manage and treat a chronic illness in the constraints of the “real world.” Not only are there an infinite number of unique situations in which the patient could encounter challenges that could not feasibly be addressed in the standard literature, but such materials are also limited to discussing only scientifically accepted beliefs, eliminating a world of practical tips and techniques. For the chronic illness patient, knowing how to *actually* treat oneself is just as important—if not more so—than knowing what science has theoretically shown one should do. “It’s actually the practical day-to-day living of it and your lifestyle management that you really need to be really clued up on,” reports one diabetic patient (Kerr, 2005).

With chronic illnesses, there are a number of details that can only be learned by living with the condition—from knowing how one’s body will uniquely react to certain circumstances, to obscure ways of administering treatment. These are details that are so complex and numerous that it is unreasonable to expect any medical professional without the chronic illness to understand or remember them. The best advice is gained by experience or trial-and-error from simply having to live with the illness day after day. The complicated nature of chronic illnesses also result in situations where there is no scientific explanation for the body’s behavior, so the standard medical resources fall short again. In this sense, the patient becomes wiser than the medical field. The need for advanced strategies to counter the nuances of treatment is something that can be better provided from people living with the condition than medical professionals.

Finally, official medical resources are subject to time and liability restrictions. Although chronic illnesses require intense monitoring and regular interaction with medical professionals, they are infrequent and available for a short-period of time when they do occur. Questions and concerns that are in between the urgency of a regular visit and in an emergency room visit may go unanswered, despite the need for a solution. As Fox (2007) reported from one e-patient, “Doctors are always in a hurry... [I need to] find out information that the doctor hasn’t shared with me, but is important for me to understand my disease.” It is not reasonable to expect to address with a medical professional all the little questions that arise in the daily treatment of a chronic illness. Even if it were the case, this assumes that the medical professional knows the answer and can comment without risking his or her medical liability, a situation that would frequently be the case for the non-scientifically-tested tips patients discover.

One of the many challenges of coping with a chronic illness is the difficulty of building a social support group with other members experiencing the same chronic illness. Chronic illness patients are a population that is frequently isolated. Some are relatively rare illnesses, limiting the number of potential relationships that could occur. Others have no visible evidence, so people coping with similar circumstances may already exist in social networks without either person realizing it. Hospitals and other medical treatment centers have strict privacy policies that restrict disclosure of personal information that could otherwise unite patients. Even though some chronic illnesses have a strong genetic component, it is not expected that family members will also have the chronic illness. The support of family and friends is an important part of coping with a chronic illness, but it is not at the same level of another person sharing the same chronic illness.

Email exchanges, blogs (and their corresponding comment sections), discussion forums, chat rooms and social networking websites are all forums where online support communities can develop. For a full overview of the main types of computer-mediated communication systems and specific examples of their use in the health and chronic illness realm, see Table 1 from Bender *et al.* (2008) below or the Murray *et al.* (2009) review. With the exception of wikis and social bookmarking sites (which are less focused on support and more on information sharing), all of the social technologies listed have a great potential to benefit chronic illness populations. Rather than focusing on the attributes of these social technologies, though, it is more useful to understand the emerging role and benefits that they collectively serve for health populations.

The intersection of health issues with interactive technology and web-based community systems is a relatively new trend, as it is a relatively new research area (Street *et al.*, 1997). Similarly, the intersection of psychological interventions and social support networks with interactive and web-based community systems is an emerging phenomenon and research area (White & Dorman, 2001). Accordingly, combining all three—with a focus on chronic illness populations—is an area even less explored. Some research has found that there is an “increasing body of anecdotal and descriptive information on the self helping processes in virtual communities, indicating that virtual communities are in fact the single most important aspect of the web with the biggest impact on health outcomes (Eysenbach *et al.*, 2004).”

Before closely examining the growing web presence of social support groups, it is important to recognize the research on in-person support groups and their impact on health outcomes. There has been nearly thirty years of research showing the effectiveness of in-person support groups in improving health outcomes, which includes enhanced quality of life, improved decision making and increased survival time (Berkman *et al.*, 2000; Spiegel, 1994).

TABLE I Computer-mediated communication (CMC) formats

<i>Format</i>	<i>Description</i>	<i>Example</i>
E-mail	A software application that allows one or more people to exchange information by sending a private or individual message.	A patient could send a friend a message by e-mail updating her on her medical condition.
E-mail list	A software application that manages the exchange of multiple messages by e-mail. A message sent to the list by an individual member is distributed to all subscribed members.	The Association of Cancer Online Resources (www.acor.org) offers more than 150 e-mail lists for people affected by cancer and related disorders.
Message or bulletin boards or discussion forums (asynchronous)	A Web-based application that “threads” messages and related replies, providing a forum for discussing various topics. The messages are not sent to individual addresses, but can be read by anyone with Internet access.	Yahoo!Groups (ca.groups.yahoo.com) is a prominent discussion forum provider, which, as of March 2008, listed more than 6000 groups dedicated to cancer.
Chat rooms (synchronous)	A Web-based application that provides a discussion “area” that accommodates synchronous (real-time) exchange of information. Multiple discussions can occur simultaneously, as result chats are often moderated.	OncoChat (www.oncochat.org) is an online support network that provides opportunities for people affected by cancer to communicate with each other in real-time.
Blogs (web logs)	A Web-based journal or diary in which entries are added by one or more authors usually in chronologic order. Readers can add comments to each blog entry, further contributing to the content.	The Migraineur (migraineur.wordpress.com) is a blog created by a migraine sufferer. The author shares her daily struggles with migraines, prompting other migraine sufferers to provide comments about their own experiences.
Wikis	A Web-based application that allows users to freely write and edit online material without using other software applications or uploading files to a server. The term wiki originated from the Hawaiian phrase “wiki wiki,” meaning quick.	Popular examples of health wikis include www.wikihealth.com and www.wikicancer.org . Users of these sites can contribute content directly to the site, providing a collaborative or social element to knowledge-building.
Social bookmarking	A Web-based application that an individual can use to save and share favourite Web sites with others online. The individual submitting the saved Web page labels or tags it with various key words, so that readers can search for relevant information by using the key word tags.	del.i.cious and www.digg.com are examples of sites that offer centralized bookmarking of a third-party site’s content; other sites permit tagging of local-site content.
Social network sites	A Web-based service that allows individuals to construct a profile, articulate a set of other people on the service with whom they share a connection, and view their list of connections and the lists made by others. Social network sites usually contain many Web-based applications that allow users to interact and share resources in different ways.	PatientsLikeMe (www.patientslikem.com) is social network site for people with life-changing diseases. Users construct personal profiles that provide information about their disease experiences, establish connections with other users of the site, and share supportive information and resources.

Today, though, there has been a shift towards the web for social support, especially in relation to health communities. McMillan (1999) estimated more than 100,000 interactive and user-friendly Internet sites dedicated to specific diseases. Just as in-person support groups positively impacted participant's health outcomes (Berkman *et al.*, 2000; Spiegel, 1994), similar results have been shown for web-based groups (Bender *et al.*, 2008; Eysenbach, 2003; Eysenbach *et al.*, 2004; Gustafson *et al.*, 1998; Gustafson *et al.*, 1994; Kalichman *et al.*, 2003; Shaw *et al.*, 2000). Fox *et al.* (2000) from the Pew Research Center report that "the public has actively adopted the Internet for health communication, and over half of these users *say [sic]* it improves their health."

In addition to the health benefits, the use of web-based support systems has also been shown to be effective for psychological support. According to Walther *et al.* (2005), "online communicators are no less effective emotionally when relying on words alone than are counterparts in face-to-face interactions, who have both words and nonverbal cues at their disposal." Kalichman *et al.* (2003) found that "among Internet users, Internet use for health-related purposes is associated with more positive coping responses and social support."

Specifically examining chronic illness populations, Fox (2007) reported that "57% of e-patients with chronic conditions say the information changed the way they cope with a chronic condition or manage pain, compared with 36% of other e-patients." An extensive meta-analysis review on people with chronic disease and Interactive Health Communication Applications (IHCAs) by Murray *et al.* (2009) concluded that "IHCAs appear to have largely positive effects on users, in that users tend to become more knowledgeable, feel better socially supported, and may have improved behavioral and clinical outcomes compared to non-users."

Kerr (2006) found that “many participants favored online peer support and electronic discussion groups [to in-person support groups], seeing them as a nonjudgmental source of support from people facing similar issues and challenges, available 24 hours a day.” This is particularly promising for the success of online communities with chronic illness population because their frequent isolation may make the web “the only way to communicate with others who are dealing with similar problems (White & Dorman, 2001).”

Given the restricted resources of chronic illness populations with respect to not only those “dealing with similar problems,” but also with respect to the inadequate relationships and resources of medical professionals and the life-dependent daily treatment and coping demands, chronic illness populations actively seek additional support. This motivation and constant drive to survive despite their health circumstances distinguishes chronic illness patients from other health populations.

Online support communities are different than traditional health behavior education and promotion through interactive technology that Street *et al.* (1997) discuss. Though persuasive technology (Fogg, 2003) and interactive health technology have been shown to be effective when compared to non-web-based interventions (Wantland, 2004), the circumstances are quite different from chronic illness populations.

Often these types of technological interventions are focused on prevention or acute health problems. As a result, health behavior change is driven by the medical professional and more likely to encounter resistance than the patient-driven change of chronic illness populations. Unlike chronic illness interventions focused on social support, these technology systems seek to alter norms or personal preferences or exhibit some form of persuasion and education (*e.g.* visualizing the risks of cigarette use to promote smoking cessation).

In contrast to the short-lived preventative or acute health condition interventions, by their very nature, chronic illness communities have a long-term perspective on health behavior change and management. There is also a welcoming and helpful attitude persistent in chronic illness support groups. Shaw *et al.* (2000) found that contributors to online support groups felt better simply by helping others. Fox (2007) reports similar findings, in that “55% [of chronic illness users] say they felt eager to share their new health or medical knowledge with others.” This all paints an entirely different picture than offering support to a highly-motivated, support-seeking community with long-term, shared health challenges.

The attributes of online support communities make them an ideal medium for chronic illness populations that have a particular need for social support and quick access to more advanced illness strategy information. White & Dorman (2001) overview some of the main attributes of online support groups, summarizing that “online support groups provide support, encouragement and information to their members...Time, space and geographic boundaries [do not restrict online] support groups. Membership in online groups...may be unlimited and not contained by international boundaries. Availability 24 h[ours] a day, 7 days a week makes online support groups convenient and accessible at user discretion.” Additionally, the aspects of the therapeutic value of writing, ease of inexperienced users learning how to use a computer and interact with the community, and archived and searchable information make online supportive communities an appealing medium. User anonymity and the existence of a collaborative knowledge resource specifically contribute to the fit of online support communities for chronic illness populations. While some traits are universally important to users—like accessibility and freedom from time boundaries—others are particularly important for chronic illness populations.

As previously stated, chronic illness patients do not have adequate support from the standard medical resources and professionals, so the “support and encouragement and information to members” is very important to this survival-motivated population. The lack of restriction across “space and geographic location” can be particularly important for some chronic illness patients because their difficulties with mobility are not a concern with an at-home connection to the support group.

“Availability 24 h[ours] a day, 7 days a week” means that a question related to a health concern—however insignificant—could be addressed without needing to wait for a scheduled visit with a medical professional. Since chronic illness treatment takes a significant amount of time and thought on a daily basis, it is expected that many questions arise that are not urgent or are too detailed to discuss with a medical professional. These questions would otherwise be forgotten or left-unanswered. Although some clinics have established phone hours to answer questions like this, this feature is not as accessible as the internet. Being able to ask questions and seek answers at any time is especially important to chronic illness populations who may encounter unexpected problems at odd hours. Online communities are a useful medium for addressing this specific need for additional help when medical professionals are not available or are unsatisfactory resources.

Anonymity is another very important trait of online communities that chronic health patients need. Often the questions facing a person with chronic illness are very sensitive and personal because of the close connection between chronic illnesses and survival; but anonymity online protects patients from this fear. “There is less reason to hold back and less fear of embarrassment [in online communities] since the confessions are unlikely to run into each other elsewhere or share information with people in other domains of their lives (Walther *et al.*,

2005).” Along with this personal anonymity is physical anonymity in the ability of a computer to mask problems with speech and hearing that may occur in chronic illness populations.

Though it could be argued that the lack of in-person contact is a weakness of online support communities, it is not necessarily a limiting factor for chronic illness populations because they tend to bond immediately through their struggles and shared experiences (*e.g.* dealing with people who can relate to their experience, specific treatments, *etc.*). Walther *et al.* (2005) referred to this concept of common experience as ‘homophily’ and notes that the way online support groups bring out homophily is “one of the most striking benefits of online support groups.” Further more, Walther *et al.* (2005) argue that “weak ties” are important to chronic illness populations because “close friends and family members may become uncomfortable, and are often ineffective, when trying to help patients or other people with problems address their concerns.” Through this common trait of homophily in chronic illness populations, they are more likely to unite in ways that other, random online acquaintances cannot build upon.

Of course, the value of the ‘community’ part of ‘online communities’ cannot be overlooked. As a whole, members collaboratively contribute to the knowledge contained within the system, making it an exceptionally rich resource for any other individuals who are coping with the same chronic illness. Building on their common experience, members can offer advice and highly specialized information about their chronic illness experience, as well as encourage and empower other members. These are attributes that most other medical resources cannot provide. As was previously mentioned, chronic illness populations are also frequently isolated, so there may be no other outlet for people to discuss their thoughts, joys, challenges or questions than an online community. The advanced information and skills provided by online chronic

illness communities, in combination with their social support, enables them to aid chronic illness patients in ways that no other resource is able to.

By examining the attributes of online support communities and their specific relevance to chronic illness populations, it is easy to see how they are ideally positioned resources for each other and are a positive partnering that should be further pursued. But, while the attributes of online communities make them an ideal means to benefit and support chronic illness communities, there are some limitations and practical concerns.

White & Dorman (2001) address a number of concerns in their review, such as the lack of or limited internet access for most of the world, the potential for misinterpretation of a message due to lack of in-person cues and the risk of inaccurate information. The concern of inaccurate or misleading information is typically solved by the community as a whole, in which members may correct statements or offer alternative explanations. Ultimately, though, the patient must choose who to believe amidst the dynamic, nearly democratic process of online communities. Users should recognize that the support is provided by other members coping with the same chronic illness who are more likely than medical professionals to be the experts on any component of coping with the specific chronic illness. Medical professionals, though, are uncomfortable with this and concerned with how patients might make ill-informed choices based on inaccurate information.

The role of medical professionals in online support communities is also unknown. Many are organically formed consumer groups, un-moderated and open to anyone. Whether medical professionals should be involved in the community as contributors or content monitors is still a question that remains unanswered. The role of online support communities in official treatment regimens is also unknown. Will participation become a part of the chronic illness treatment

routine? Can certain communities be endorsed or recommended by the medical community? Should medical professionals or health insurance companies be the ones to economically and technically sustain online communities? Who takes responsibility for the ambiguity of online communities?

Like many other phenomena on the internet, the success of a specific online community may lie in “viral” propagation of the group or other organic, random discoveries. Explicit intentions to create a community and try to recruit or force patients to participate may therefore prove to be unfruitful. It is tempting to think that creating what seems to be an ideal online community will be beneficial to its intended members, but if the system does not, for example, build a sufficient and dedicated membership pool, the tool will be ineffective.

Similarly, online communities are very hard to study. Users are difficult to track and an accepted method to measure the effectiveness of an online community does not yet exist (Eysenbach *et al.*, 2004; Murray *et al.*, 2009). Although the new emergence of the field means there is a scarcity of research in the area of online communities for chronic illness populations, the “absence of evidence does not mean that virtual communities have no effect (Eysenbach *et al.*, 2004).”

With these limitations and practical concerns also come a number of research questions. At the core of nearly all the questions is the lack of an accepted evaluation method for online communities and, as a result, a way to distinguish the effectiveness on health and knowledge benefits from using online support communities. Although Murray *et al.* (2009) propose a theoretical pathway by which online communities may be effective, there is still not a clear understanding of how they may moderate or mediate health benefits or change.

Are certain chronic illness populations more or less able to benefit from online communities? Are any of the many types of computer-mediated communication systems (see Table 1) more effective overall for chronic illness populations? There is likely to be a continuum for the potential impact online communities may have on specific chronic illnesses, as Davidson *et al.* (2000) found that “support groups ‘proliferated’ for more embarrassing, stigmatizing or disfiguring conditions” and “favored conditions that were poorly understood, difficult or impossible to cure, or were overlooked by traditional health care.”

Do socio-demographic factors such as age or gender alter the effectiveness or perceived value of the online support system? Klemm *et al.* (1999) report that “men are twice as likely to give or ask for information related to a disorder, while women use the [online support] group to share personal experiences and provide encouragement and support,” but there still exists a huge potential to discover more about these socio-demographic differences.

White & Dorman (2001) mention that variations in activity and interaction exist among users, indicating that varied health outcomes could result. Some members are active contributors of either or both questions and responses, while others are “lurkers” who gain knowledge and support as an observer of the community. Just as mental rehearsal is an important part of coping and of cognitive behavioral therapy, perhaps being a “lurker” is a similar and equally effective means of benefiting from the rich resources of the community. Other related questions exist around the technical relationship of members to the online community. Is there a difference between online communities with public access versus private, invitation-only membership? Are communities revolving around blogs or other non-membership-based systems still effective? What effect might a supplementary in-person support group play for the online community?

Beyond these social technologies and online communities, exploration of handheld computing and mobile devices should also be explored. Their ability to offer support away from the traditional computing platform may make them an even more powerful tool for chronic illness patients who may unexpectedly encounter challenging problems on-the-go. Just as users can participate in mobile chat rooms or micro-blog (*i.e.* 'tweet' on twitter) about work or pleasure, the chronic illness patient could use this forum to ask a question and receive immediate feedback. Although many of the same resources of traditional computer-based communication systems are available on handheld and mobile computing devices, it is not known what the effect that changing the technological platform will have on providing the support and information needs of chronic illness populations.

Recognizing the specialized, dynamically-changing advanced information needs of chronic illness populations that are not and cannot be adequately addressed by the standard medical professionals or education materials, online community systems and social technologies may be a more appropriate and beneficial means to satisfy the daily questions and concerns of chronic illness populations. By their very nature, online communities and other social technologies provide an appropriate means to positively address this need.

References

- Bender, J. L., O'Grady, L., & Jadad, A. (2008). Supporting cancer patients through the continuum of care: a view from the age of social networks and computer-mediated communication. *Current Oncology*, *15*(2), S42-S47.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*(6), 843-857.
- Davidson, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, *55*(2), 205-217.
- Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA: a Cancer Journal for Clinicians*, *53*(6), 356-371.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ*, *328*(7449), 1166.
- Fogg, B. (2003). *Persuasive technology: using computers to change what we think and do*. San Francisco: Morgan Kaufmann Publishers.
- Fotheringham, M. (2000). Interactive health communication in preventive medicine: Internet-based strategies in teaching and research. *American Journal of Preventative Medicine*, *19*(2), 113-120.
- Fox, S., Rainie, L., Horrigan, J., Lenhart, A., Spooner, T., Burke, M., Lewis, O., & Carter, C. (2000). *The online health care revolution: How the Web helps Americans take better care of themselves*. Pew and the American Life Project. Report retrieved April 2009 from <http://www.perinternet.org/reports>

- Fox, S. (2007). *E-patients with a disability or chronic disease. Pew and the American Life Project*. Report retrieved April 2009 from <http://www.pewinternet.org/reports>
- Gustafson, D. H. (1999). Consumers and evaluation of interactive health communication applications. *American Journal of Preventative Medicine, 16*(1), 23-29.
- Gustafson, D. H., Hawkins, R., Boberg, E., Pingree, S., Serlin, R. E., Graziano, F., et al. (1999). Impact of a patient-centered, computer-based health information/support system. *American Journal of Preventative Medicine, 16*(1), 1-9.
- Gustafson, D. H., Wise, M., McTavish, F., Otis Taylor, J., Wolberg, W., Stewart, J., et al. (1994). Development and pilot evaluation of a computer-based support system for women with breast cancer. *Journal of Psychosocial Oncology, 11*(4), 69-93.
- Kalichman, S., Benotsch, E. G., 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*(1), 111-116.
- Kerr, C. (2006). Internet interventions for long-term conditions: patient and caregiver quality criteria. *Journal of Medical Internet Research, 8*(3).
- Klemm, P., Hurst, M., Dearholt, S. L., & Trone, S. R. (1999). Cyber solace: gender differences on Internet cancer support groups. *Computers in Nursing, 17*(2), 65-72.
- McMillan, S. J. (1999). Health communication and the Internet: relations between interactive characteristics of the medium and site creators, content, and purpose. *Health Communication, 11*(4), 375-390.

- Murray, E., Burns, J., See Tai, S., Lai, R., & Nazareth, I. (2009). Interactive Health Communication Applications for people with chronic disease. *Cochrane Database of Systematic Reviews*, (4).
- Neuhauser, L., & Kreps, G. L. (2003). Rethinking Communication in the E-health Era. *Journal of Health Psychology*, 8(1), 7-23.
- Nguyen, H. (2004). Internet-based patient education and support interventions: a review of evaluation studies and directions for future research. *Computers in Biology and Medicine*, 34(2), 95-112.
- Shaw, B. R., McTavish, F., Hawkins, R., Gustafson, D. H., & Pingree, S. (2000). Experiences of women with breast cancer: exchanging social support over the CHES computer network. *Journal of Health Communication*, 5, 135-159.
- Spiegel, D. (1994). Health caring. Psychological support for patients with cancer. *Cancer* 74(S4), 1453-1457.
- Street, R. L., Jr., Gold, W. R., & Manning, T. (1997). *Health promotion and interactive technology: theoretical applications and future directions*. LEA's Communication Series. Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Walther, J., Pingree, S., Hawkins, R.P., Buller, D. (2005). Attributes of interactive online health information systems. *Journal of Medical Internet Research*, 7(3).
- Wantland, D. (2004). The effectiveness of web-based vs. non-web-based interventions: a meta-analysis of behavioral change outcomes. *Journal of Medical Internet Research*, 6(4).
- White, M., & Dorman, S. (2001). Receiving social support online: implications for health education . *Health Education Research*, 16(6), 693-707.