St. Catherine University

SOPHIA

5-2013

Peer-to-Peer Online Support and its Role in Patient Education

Carol Grady
St. Catherine University

Follow this and additional works at: https://sophia.stkate.edu/ma_nursing

Peer-to-Peer Online Support and its Role in Patient Education

Carol Grady

Saint Catherine University

Time travel back to 1993, and imagine you are a parent whose first child has been diagnosed with a rare syndrome. It's a condition you've never heard of, does not appear in popular press or literature. You are forced to rely on your pediatric neurologist, who does not have the best communication skills, for an explanation of your child's condition. Given that this syndrome's outcomes tend to be unfavorable, this physician does not want to provide you with too much information for fear it will be too much for you to handle. At this point in time, widespread use of the World Wide Web is still a decade away and you have no access to a medical school library. The condition is so rare there are no support groups or organizations available to you, with the result being that you feel more alone and isolated than ever. Finally, your mother tells you about someone she works with who has a cousin that lives halfway across the country with a child that has what it sounds like yours has. You call long-distance and connect with the mother, discovering that you do have children with the same syndrome. It is this mother, rather than your physician that breaks the news to you that children with this diagnosis do not typically make it to college. This mother becomes your first pillar of support as you begin your journey as a parent of a child with special needs. You will never meet her face-to-face.

The previous scenario is a true example. With information just a mouse click away, it is becoming difficult to recall the not-so-long ago days when people were limited in their ability to search out others and access immediate information. As recently as the 2000s, people newly diagnosed with a rare condition would contact the National Organization for Rare Diseases (NORD) via mail or telephone, in the hopes of being connected with somebody else in the world with their specific diagnosis. They would then have to wait for weeks or even months for a match. Today, they can go online and

almost immediately access not only a match but an entire global community. Furthermore, the birth and evolution of social media has transformed communication in such a way that the dialogue these groups are able to engage in is of a two-way, interactive nature.

The question must be asked, is peer-to-peer online support an efficacious form of patient education? What kind of support are patients receiving from these communities? Is this a culturally inclusive form of patient education? Nurse educators need to be asking these questions, to better educate staff nurses as well as patients themselves and to help shape future iterations of these technologies. Although there has been a lot written about this topic, there is a definite knowledge gap, with technology getting out ahead of any established use protocol. In lieu of solid research, nursing has not come to any definitive consensus yet on what constitutes best practice and there is concern that patients are receiving erroneous information that could harm them. Quality studies are needed to create evidence-based practice and to help create standards and guidelines for use. Yet researchers are challenged as technology continues to evolve at a rapid pace. As new technology platforms and websites are developed, it is hard to imagine that use patterns will remain static, representing a potential obstacle for longitudinal study. The purpose of this paper is to examine these questions and offer any recommendations that come from this analysis.

Background

The advent of home personal computers and mobile devices, along with the rise of the Internet, has launched a radical transformation in the way patients interact with their providers and each other. Through use of the Internet, patients have been able to

coalesce and exchange empowering support and information in ways previously

unimaginable. There remains a question as to whether or not digital patient interactions

deliver better health outcomes. This paper explores technology's impact on patient self-

advocacy, the rise of online support groups, research, and several key exemplars of peer-

to-peer online support.

Patient Self-Advocacy in the Information Age

As the World Wide Web became a reality and the Internet became mainstream,

businesses began to harness this power tool to improve efficiency and service. Health

care institutions, however, were still operating in an archaic manner, despite prime areas

of care that had enormous potential for improvement. Once federal mandates and

incentives for creation of an electronic health record (EHR) were instituted, the industry

began to shift priorities and modernize its operations in earnest. Consolidation in the

industry also fueled this shift.

Health consumers, however, were poised to step out ahead of the curve in their

desire to learn more about their health conditions. In his 2007 white paper on e-patients,

Tom Ferguson writes about a patient who in 1992 had had to resort to impersonating his

physician in an attempt to gain access to a medical journal to learn about a condition he

had recently been diagnosed with (Ferguson, 2007). Five years later, in 1997, free online

Medline searches were made available to the public (Nelson, Joos, & Wolf, 2013). With

the migration of databases to the Internet, the cloistered world of medical research was no

longer limited to academics and health care professionals. Patients were now able to self-

educate themselves about their conditions in ways that had previously been controlled by

health care providers. They began to ask more questions of their providers, sowing the

seeds for the participatory medicine movement. This was, however, still the late '90s, early 2000s' world of Web 1.0, with static, non-interactive websites and communication flow limited to one direction (Nelson et al, 2013).

Patient as Consumer

In the late 20th Century and early into this century, the business model of health care began to rapidly change. The industry began to realize that the traditional fee-for-service model was not sustainable, with health care becoming increasingly viewed as a commodity. Not surprisingly, along with that commodification, patients started to be viewed as *consumers*, a metamorphosis that has had mixed blessings for patients and health care entities alike.

The consumer movement of the 1960s and '70, grew out of a society being increasingly inundated with advertising and a proliferation of products available for purchase. As the public began to question the truthfulness of claims made by advertisers, along with press investigations on products that were ultimately unsafe, there increasingly arose calls for protection of the people who purchased these goods. Sellers were still sellers but buyers started to be called something else – consumers, as one who consumes goods or services.

As health care as a business began to transform itself in the 1980s and '90s, the concept of health care consumers was hatched and at times this term would be used in place of the traditional term patient. Yet as Nelson et al. point out in their 2013 book, *Social Media for Nurses*, patients and consumers carry two very different connotations. A health care provider provides care to a patient and there exists a relationship defined by care and structured around that word (Nelson et al, 2013). A financial transaction takes

place but the emphasis is on the service. A consumer, however, is someone who purchases and takes in a good or service and the emphasis is on cost, rather than care (Nelson et al., 2013). The consumer may not be the one to pay for the product but with this terminology there is no doubt a monetary remuneration has or will take place.

Patient and consumer also carry distinctly different word associations. The Hippocratic oath, trust, and heal are words associated with patient. Consumerism carries quite other connotations: empowerment, transparency, rights. The consumer movement, transposed into the health care world, has prompted patients to be more questioning and become more empowered. No longer passive or acquiescing to physician directives, patients have started to want to have a say in their care and in their treatments (Ferguson, 2008). They want a more equal partnership and greater accountability. The concepts of patient-centered care and family-centered care were conceived in this transformed arena. Yet as health care costs continue to mushroom and the industry consolidates, the elements of a perfect storm have begun to convene. As the cries for health care reform mount, consumers are harnessing the Internet to reach out to others.

The Evolution of Social Media

Generally speaking, people had begun reaching out to each other via computers years before the World Wide Web appeared in the public conscious. In the late 1970s and early '80s, social networking was limited to postings through bulletin board-type systems, largely only available to universities, research institutions and the military. Once personal computers (PCs) entered the marketplace, social networks expanded to online subscription networks, such as CompuServe and Prodigy. Media sharing sites,

along with the initial browser-based social networking sites, such as Friendster

(http://www.friendster.com/), were developed in the early 2000s.

However, it was the evolution of Web 2.0, a term conceived of by Tim O'Reilly

in 2004, which facilitated the advent of social media as it is known today. The Web 2.0

era was ushered in with faster connection speeds, better processors, more user-inspired

software, and more sophisticated and often free Web tools. Web 2.0 transformed the web

experience, making it a "richer" user experience and liberated it from a static screen, PC

platform (O'Reilly, 2005). Social media use exploded, as users became able to directly

interact with each other.

Social media can be broken down into several categories. These include *blogs*,

usually taking the form of an online journal; *microblogs*, a condensed version of a blog,

which posts more often and is usually constrained by a specific wordcount; *social*

networking sites, consisting of an online portal that allows users to set up a profile and

post text, photos, and video, while at the same time allowing others to post comments

about the user's entries and vice-versa (blogs allow this commentary also, however the

focus with social networking sites is to link users together in webbed network; and

finally, *photo/video/file sharing sites*, where users upload and post various media, often

self-created (Eckler, Worsowicz, & Rayburn, 2010). Another social media tool is a wiki,

which is a website or application that allows a prescribed group of users to comment and

collaborate in a shared space.

Patients are searching out each other and communicating via these new and

creative Internet vehicles, enlisting " social network site blogs, online communities, email

groups and listservs, and other tools," (Fox, 2011). In a 2010 telephone survey conducted

by Princeton Survey Research Associates International (PSRAI) on behalf of the Pew

Internet Project and the California HealthCare Foundation, 23% of Internet users living

with a chronic condition had searched online to find someone with a health situation

similar to theirs (Fox, 2011).

Online Support Communities

Health condition support groups have a long history, the most famous being

Alcoholics Anonymous (AA), which has been in existence for nearly 80 years, offering

support in the form of weekly meetings. Julie Gordon's Mothers United for Moral

Support (MUMS) organization, started in the late 1970s, is just one example of a

newsletter/support group that grew out of word-of-mouth and was distributed via the

mail. Over the years Gordon compiled a database of over 26,000 families in over 56

countries, covering more than 3,500 disorders (MUMS, n.d.). However, with the power

and speed of the Internet, support groups have changed dramatically with the

establishment of virtual online communities.

Merriam-Webster's 11th edition dictionary defines community as "a body of

people living in the same place under the same laws," (2004). Contrast that to Porter's

definition of virtual communities coined the same year: "A virtual community is defined

as an aggregation of individuals or business partners who interact around a shared

interest, where the interaction is at least partially supported and/or mediated by

technology and guided by some protocols or norms," (Porter, 2004). In her article, Porter

pointed out that there was a lack of consensus among researchers on a definitive

definition of the term virtual community and she therefore crafted a definition that

embraced pieces of previous definitions, while broadening the overall scope. Nelson et

al. (2013) take this a step further in their book, defining virtual community as "a gathering of individuals who share a common interest, focus, or need, who use an Internet platform to frequently interact with each other, and who identify with the predefined community, which provides a sense of belonging or ownership," (p. 107).

The Reasons for Online Support

In the most recently published Pew Research Center report, it was noted that 35% of U.S. adults have specifically gone online to find more information about a medical condition (Fox & Duggan, 2013). In a survey of Internet users, 72% said they looked online for health information within the past year (Fox & Duggan, 2013). Surprisingly, half of all health information searches are done by a surrogate (Fox et al., 2013). These Internet surrogates are people, often caregivers, who are searching on behalf of a family member or friend confronted with a medical situation (Ferguson, 2008). Typically surrogates are women and their efforts online do have ramifications on medical care, impacting decisions made not only for their loved ones but also influencing their own health care as well (Ferguson, 2008).

E-Health

It is important to note that health care has been transformed in parallel with the Internet. The term e-commerce was appropriated by the health care industry and has metamorphosed into the term, *e-health*. One of the widely accepted definitions of e-health is that coined by Eysenbach (2001), in his article, "What is e-health?": "e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical

development, but also a state-of-mind, a way of thinking, an attitude, and a commitment

for networked, global thinking, to improve health care locally, regionally and worldwide

by using information and communication technology." He writes there are 10

components of e-health: efficiency; enhancement of quality of care; evidence based;

empowerment of consumers and patients; encouragement of a new relationship between

patient and health professional; education of physicians through online sources and

consumers; enablement of information exchange and communications in a standardized

way; extension in scope of health care beyond traditional boundaries; ethics; and equity

(Eysenbach, 2001).

E-Patients

Certain traits from a group of online health care consumers provide the basis for

adoption of another term: *e-patient*. This term grew out of the participatory medicine

movement, with Dr. Tom Ferguson, founder of the e-Patient Scholars Working Group,

describing e-patients as empowered, engaged, equipped, and enabled (deBronkart, 2013).

E-patients are also internet-savvy and use these skills to ferret out health information for

education and decision-making (Gallant, Irizarry, Boone, & Kreps, 2011). Ferguson's

workgroup divided e-patients into three categories: the well, made up of approximately

60-65% of e-patients; the acute, constituting five to six percent, and defined as those with

a new medical concern or challenge; and the chronics, at 30-35%, with stable chronic

conditions (Ferguson, 2008). This was derived from an earlier model in a report by Cain,

Sarasohn-Kahn, and Wayne (2000), that had created three divisions: the well, the newly

diagnosed, and the chronically ill and their caregivers. Although the term had been

introduced earlier, the term consumer informatics was first used by Ferguson in

professional literature in 1995 (Nelson et al., 2013). Ten years later, he co-authored an

editorial article with Dan Hoch, an epilepsy specialist in the Department of Neurology at

Massachusetts General Hospital, that outlined lessons learned from e-patients (Hoch &

Ferguson, 2005). Although written by health professionals, this editorial summarizes

quite clearly the different types of peer support that patients are looking for in turning to

online communities. Not only do they include emotional and social support, they also

offer practical advice in how to live one's life when dealing with a new diagnosis or a

chronic condition, offering how-to's, reviews on treatments and providers, as well as the

opportunity to tell their stories (Hoch & Ferguson, 2005).

These supportive interactions foster a sense of community within users (Nelson et

al, 2013). In 2004, Hoch and several colleagues conducted an observational study to

examine how e-patients used online support groups, focusing their attention on an

epilepsy support group on the website, BrainTalk Communities

(www.braintalkcommunities.org/forum.php). "What we found surprised us. We assumed

that most interactions would be support related, with some members describing their

medical experiences and others offering active listening, sympathy, and understanding.

But while such interactions were an important part of the group process, they were

observed in only about 30% of the postings. In the remaining 70% of the postings, group

members provided each other with what amounted to a crash course in their shared

disease, discussing topics such as the anatomy, physiology, and natural history of the

disorder; treatment options and management guidelines for each form of treatment; and

treatment side effects, medical self-management, the day-to-day practicalities of living

with the disease, and the effects of their condition on family and friends," (Hoch &

Ferguson, 2005, p.0728-0729). It is this need to connect with others like themselves that

gave rise to such web sites as PatientsLikeMe, as well as the proliferation of formal and

informal groups and organizations across the web.

The Theoretical Underpinnings of Online Support

The widespread use of the Internet is a relatively recent phenomenon and its

impact on our society and cultural norms has been dramatic and continues to reverberate.

Two different theoretical frameworks support and illustrate this change. Everett Rogers'

Diffusion of Innovation Theory provides an explanation for how technology and ideas

move through a population. Malcolm Knowles' Adult Learning Theory is a cornerstone

of adult learning and explains not only how adults learn but their motivation in doing so.

Rogers' Diffusion of Innovation Theory (DOI)

Rogers' DOI theory is emblematic of the rise of the Internet and social media. A

change theory that explains how technology and ideas are adopted by a society over time,

Rodgers constructed a model consisting of five phases that illustrates how innovation

spreads. An idea starts with knowledge, followed by persuasion, which leads to a critical

decision junction whereby the idea is either advanced into adoption and confirmation or

is rejected and jettisoned (Rogers, 1995). Rogers breaks down the characteristics of

adopters and the rate at which they adopt into five groupings: innovators, early adopters,

early majority, late majority, and laggards (Rogers, 1995). This model is representative

of our society's adoption of the Internet and its various platforms and applications, such

as online banking, online shopping and the use of social networking sites.

Knowles' Adult Learning Theory

An elemental staple to the teaching of adults, Malcolm Knowles' Adult Learning Theory distinguished adult learning from child learning. Childhood learning is subject-centered, whereas adult learning is problem-centered. Primarily, adult learners seek knowledge for the purpose of immediate problem solving (Bastable, 2008).

In accessing the Internet to connect with online support groups, people are seeking information and help for a health problem; their own or that of a loved one. Knowles' theory encompasses the motivation of why people do this. Coupling it with Rodgers' DOI theory, these frameworks provide the means and motivation of how adults in the 21st century are turning to new models for support and information.

A Review of the Literature

Although there has been much published, there appears to be a gap in the literature with respect to research studies on this subject. The research is in its infancy and the published studies lack rigor and depth. A number of published systematic reviews confirm this. In terms of published research studies, there are a number of smaller studies that have appeared in peer-reviewed journals, though a large number of these are within less well-known, online journals. Many of these studies have focused specifically on online cancer support groups

Psychosocial Benefits

Psychosocial support is often the type of support associated with support groups. It facilitates a sense that one is not alone and helps to foster emotional well-being and the chance for reflection. In today's busy, billing-driven clinic world, this type of support may be lacking or insufficient in a clinic setting. Therefore, these websites may be providing an essential coping tool to many patients, particularly women (Fox, 2013).

Psychosocial Benefits Research

In 2005, Rodgers and Chen published the results of a longitudinal study that examined the psychosocial benefits of participation in an online community for women with breast cancer. The investigators used a multi-phase, multi-method design, observing postings on an asynchronous bulletin board of an online breast cancer community over the course of three years. The researchers used a combination of a cross-sectional and longitudinal sampling frame, randomly selecting a one-week period to initially observe and then drawing a random sample of 100 participants from within that week's postings. They then followed these participants' postings over the course of the study, as well as pulling subjects' archival data, in order to more fully flesh out the women's stories. The study was divided into three phases, with content analysis of postings occurring throughout all three phases; thematic analysis occurring during phase two; and content analysis of member profiles occurring within phase one and phase three.

Thematic analysis revealed a number of psychosocial benefits derived from participation. These include "information exchange, social support, improved affect toward the discussion board, greater optimism toward breast cancer, increased skill or ability to cope with the disease, improved mood, decreased psychological distress, and strategies to manage stress," (Rodgers & Chen, 2005). Rodgers and Chen found that information exchange is complex and that psychosocial benefits can evolve over time. They also found a positive relationship between psychosocial well-being and the frequency of postings.

This is one of the better-designed studies that examined this subject, with rich data results and outcome findings that support the argument for the efficacy of online

breast cancer communities and peer-to-peer support. Unfortunately, the sample, though randomly drawn, is relatively small. Rodgers and Chen do however highlight how single episode research can inadvertently skew toward what the participant is feeling at that one point in time as opposed to a more accurate longitudinal depiction.

Griffiths, Calear, and Banfield reiterate a lack of quality studies on this subject in their 2009 systematic review on the efficacy of Internet support groups. Griffits et al. conducted a systematic review by sifting through three databases (PubMed, PsycINFO, and Cochrane) on available evidence of Internet support groups' ability to reduce depressive symptoms. They only included papers if they met three criteria: inclusion of an online peer-to-peer support group; incorporation of a depression outcome; and reporting of either quantitative or qualitative empirical data (Griffiths et al., 2009). This winnowing eventually yielded 31 papers, consisting of 28 studies, that were coded for Internet support group (ISG), participant and study characteristics and depression outcomes, as well as study design characteristics and quality (Griffiths et al, 2009). The authors were unable to do a formal quantitative meta-analysis due to "the low quality of the studies meeting the inclusion criteria and the heterogeneous nature of the conditions studied," (Griffiths et al., 2009). Breast cancer ISGs made up the majority of samples.

The authors noted that one-third of the studies had a randomized controlled design (RCT), but that two-thirds of those trials "failed to use an adequate method of randomization or failed to specify the method of randomization," (Griffiths et al., 2009). A minority of the 28 used a control group. Only two studies examined the effectiveness of depression ISGs for improvement of mood and both lacked the quality of design to substantiate that claim. Most disturbingly, Griffiths et al. emphasize "a trend toward an

association between significant positive findings and low design quality," (Griffiths et al.,

2009).   This is of concern on two fronts, the first being the rise in popularity of online

peer-to-peer support groups, with the popular notion being that they are effective but the

reality being that they are relatively untested in this claim; the second being that online

support groups offer great potential for "users who are isolated or not able to access

conventional face-to-face services, either due to lack of mobility or geographic location,"

(Griffiths et al., 2009). This review noted that none of the studies examined ISG use

among the elderly and only one dealt with rural populations.

        The populations omitted in these studies are potentially worrisome. As noted in

Fox's 2011 report, compared to younger users, elderly Internet users (those ages 65 and

older) are less likely to search online for others with similar health concerns (Fox, 2011).

Yet the elderly could stand to benefit from this online interaction, due to the population's

high percentage of multiple chronic conditions and tendency toward isolation. Is there a

technology knowledge gap or is there resistance to support groups? The elderly tend to

be digital immigrants with low digital literacy skills. As to rural communities, is online

access hindered by location? These are questions that could be addressed in further

research.

Knowledge Exchange as Support

        Consumers also glean support by learning about their conditions and how to cope

with them. The website, PatientsLikeMe, offers users the opportunity to connect with

patients similar to themselves and become involved in online communities. These

communities are devoted to a particular diagnosis, most notably amyotrophic lateral

sclerosis (ALS), Parkinson's Disease, and Multiple Sclerosis (MS), and share and

exchange personal health data. In exchange for these online resources, this for-profit organization hopes to change health care by bringing patients into the discussion, such as including their input on what constitutes best practice.

Research on Knowledge Exchange

PatientsLikeMe funds research and has its own research design team. In a 2010 study, this team conducted a cross-sectional survey of nearly 7,000 members from six PatientsLikeMe online communities: ALS, Parkinson's Disease, MS, human immunodeficiency virus (HIV), fibromyalgia, and mood disorders. Their objective was to determine potential benefits to members in terms of treatment decisions, symptom management, clinical management, and outcomes (Wicks, Massagli, Frost, Brownstein, Okun, Vaughan, Bradley, & Heywood, 2010). Using an internal tool, researchers created a questionnaire that consisted of a core set of questions to be answered by all respondents, as well as including community specific questions. The survey was initially piloted with PatientsLikeMe's rare disease community, with a sample size of 30. This was then rolled out to 6,825 members in the communities previously mentioned, with 1,323 returned, a response rate of 19% (Wicks et al., 2010). A data analysis was then run. Researchers also used participant web-logs to test their hypothesis that site use involvement is associated with benefit. By examining and coding user activity, researchers produced an engagement score to reflect engagement.

Although the researchers found variation between the different communities and between respondents and nonrespondents, their findings seemed to reflect that the benefits of participation were widespread (Wicks et al., 2010). Participants evaluated the website in terms of treatment decisions, symptom management, provider interaction,

diagnosis status and confidence in diagnosis, and finally comfort with sharing of medical data. Fifty-seven percent of respondents indicated that the site was moderately helpful to very helpful in helping them understand side effects of their treatment (Wicks et al., 2010). In addition, 42% reported that they were able to locate another patient who could help them to understand what a particular treatment for their condition was like thanks to the web site (Wicks, et al., 2010). Patients also were able to learn about a symptom they had experienced from the web site, with 72% reporting the web site was moderately to very helpful in this regard (Wicks, et al., 2010). In some of the most compelling findings, 70% of respondents agreed that the site improved their ability to cope with problems in their lives; 68% reported feeling less self-conscious about their condition as a result of meeting other patients through the website; 72% felt more in control of their condition; and 62% believed that it enhanced their quality of life (Wicks, et al., 2010). Although many health professionals worry about patients self-diagnosing after consulting online resources, 94% of respondents reported that they already had a diagnosis upon joining PatientsLikeMe. Participants also became more willing to share their health data and those with the most serious conditions appeared to be the most comfortable with sharing (Wicks, et al., 2010).

This study, however, has serious limitations. The most glaring is that the researchers are paid employees of PatientsLikeMe and have stock options in the company, a major conflict of interest. Also, as is true with studies involving surveys, participants self select and survey questions rely on self-report. Therefore, there is a strong potential for bias in this study.

Yet it is this collective wisdom that users are trying to tap into when they search these sites for information. A physician or a nurse cannot truthfully tell someone what it's actually like to have ALS or how to manage the disease when raising a family, despite their expertise in the condition. Providers on their own also lack the ability to pull data together to bring about innovation and improvements in treatment. As Ferguson notes in his white paper, "…unless e-patients are lucky enough to find a clinician who is a top specialist in their disease…they will be able to learn more from the Internet than they can in their doctor's office," (Ferguson, 2008). Sites like PatientsLikeMe, however, do have the ability to take their aggregate data and organize their users to push for funding for research studies.

Knowledge Exchange and Medication

One of the most notable examples of knowledge exchange that occurs with peer-to-peer support is in the area of medication use. Patients are often anxious to learn about their treatments and hear others' accounts of using medication and potential side effects. A recent study that compared consumer-generated reviews to that supplied by professionally controlled sources is Hughes and Cohen's 2011 mixed-methods study. Hughes and Cohen's research was centered on two psychotropic medications: the antidepressant Lexapro [escitalopram] and the antipsychotic Seroquel [quetiapine], two widely used agents that also offer various off-label mental health and non-mental health uses (Hughes & Cohen, 2011). This study drew its sample from two consumer-generated websites and two professionally controlled health sites. The established criteria for the consumer sites were that all consumer commentary had to be accessible to all visitors to the website, regardless of membership, and the website had to have at least 200 consumer

comments per medication. For the professionally controlled site, the major criteria were

that a team of medical professionals (typically journalists overseen by physicians)

oversee website content. Additional criteria considerations included that the website was

a commercial health portal not associated or operated by government; disclosures

revealed no conflict of interest for website ownership or sharing of professional

contributors; and recognition of excellence for content (Hughes & Cohen, 2011). The

consumer websites selected were Askapatient (www.askapatient.com/) and Crazymeds

(www.crazymeds.us/). The professionally controlled sites were WebMD

(www.webmd.com) and Revolutionhealth www.revolutionhealth.com.

A stratified simple random sample of 960 consumer reviews appearing across the

four websites was drawn, along with using the professional medication descriptions

retrieved from the two professionally controlled websites for a comparison. The

researchers then coded entries based on a tool Hughes had developed by inductively

coding 85 randomly selected consumer cases from their sampling frame, working from a

grounded theory framework, followed by data analysis (Hughes & Cohen, 2011).

The results showed that while both sets of websites reported many of the same

drug effects, the qualitative nature of their text "differed substantially in their descriptions

and in the relative frequency of mentions of certain effects," (Hughes & Cohen, 2011).

Consumers were better at putting medication effects into a context, better reflecting how

these side effects affected their quality of life, whereas professional descriptions were

involved with physical manifestations. There also appeared to be a disconnect between

the descriptive labels used in professional text in relation to consumers' perceptions of

side effect. Interestingly, although consumer reporting was varied across the websites,

consumer postings on professionally controlled sites tended to reflect more positive sentiments and less side effects. This study did have some limitations, such as an incomplete reporting of medication dosages, multiple dosage trials and additional incomplete reporting by online consumers, as well as the potential for possible inclusion of reviews of generics, rather than brand-name versions.

The topic of medication side effects and drug interactions is an extremely important area for online support users and providers alike. Providers can often have a knowledge gap of drug interactions when a patient is on multiple medications. It is often complicated and difficult to tease out. One must also strongly impart to consumers to be cognizant of who is behind these types of websites, do they have an ulterior agenda, and who ultimately owns the content and what happens to the postings. Patient education may need to include instruction on evaluation of websites (Nelson, et al, 2013).

Support During Times of Crisis

CaringBridge, founded in 1997, was created to provide families or individuals going through a health crisis, adoption, childbirth, or military service the online opportunity to keep friends and family appraised of their situation. In 2011, CaringBridge created over 70,000 communities and had over 46 million visits (CaringBridge, 2012). CaringBridge is similar to a blog but it is not interactive in the same way. Visitors can only interact with the person who created the site or for whom the site was established, with the content focused on their care.

Research on Crisis Support

Operating from a uses and gratification theoretical framework, Anderson set out to examine the social support and other benefits CaringBridge brings to its users,

specifically the web page creators (Anderson, 2011). Initially working from a pilot study,

Anderson invited via email all new site authors from January to March 2006, whose sites

had some activity to participate in a survey. Of 1,646 invites, 378 completed the online

questionnaires. Anderson refined the survey to include 145 total items and sent it out to

all authors who created sites between April to November 2006 via CaringBridge email.

Of 4,497 invitations sent, 1,035 were completed and return, yielding a 22.1% response

rate. As Anderson was focusing on uses and gratifications in this research, 45 items were

identified as benefits. Exploratory factor analysis was done to derive deeper meaning and

means were calculated to determine which benefits were highest rated. The four primary

benefits revealed were providing information, receiving encouragement from messages,

convenience, and psychological support (Anderson, 2011). Hierarchical multiple

regression analysis was also conducted, which found two variables, gender and

spirituality, to have the most variance among the top four benefits. Spiritual/religious

respondents rated three benefits higher than nonspiritual respondents: providing

information, encouragement from postings, and psychological support. Women also

rated encouragement from postings and psychological support higher than men

(Anderson, 2011).

In analyzing the study's demographics, Anderson did highlight that most

CaringBridge authors are female, Caucasian and religious. As far as women are

concerned, this result is not surprising in light of previous findings. Fox found female

Internet users significantly search for health information online more than males, 79%

compared to 65% (Fox, 2013). Women also act as health surrogates more than men

(Ferguson, 2009).   Anderson's findings, however, invite the question of where do males,

ethnic minorities and nonreligious groups receive their support when experiencing a

health crisis.

Differences in Support Use by Ethnicity

The literature seems to suggest differences exist between ethnic groups in their

embrace of online support. This is borne out in a 2008 lit review by Fogel, Ribisl,

Morgan, Humphreys, and Lyons, which examined the underrepresentation of African-

Americans in online cancer support groups. The review notes that as of 2006, African-

Americans did lag behind whites in terms of Internet access. They also though make note

of digital inequality, which refers not just to differences in Internet access but differences

among those with Internet access (Fogel, et al., 2008). African-Americans and whites

tend to have different Internet use patterns and this extends to the use of the Internet for

health applications and information. The authors also emphasize that lack of utilization

of online support is only problematic if it damages health and this has not been borne out

by the data. This review points out that African-Americans, historically religious, have

sought support from their church communities and families and that this may be a

preferred mode of support when dealing with cancer (Fogel, et al, 2008).

One should not, however, conclude that African-Americans do not use the

Internet to access health information. According to the most recent online health report

from the Pew Research Center, 51% of black and 48% of Latino adult Internet users

report searching online for health information (Fox, 2013). These use patterns, however,

may be changing. The numbers jump to 69% and 66% when the wording is changed to

reflect the percentage of Internet users, irrespective of adults. One must ask if teens in

these communities are turning to the Internet more for online support.

This recent report also highlighted access and use differences. Of the 85% of

U.S. adults that own cell phones, 35% of blacks cell phone owners report using their

mobile device to look for health or medical information online, and 38% of Hispanic cell

phone owners have done so as well (Fox, 2013). As a comparison, whites report using

their phones 27% to look up health information.   In light of this data, Fox's earlier 2011

report confirms that different ethnic groups tend to show variation in the type of online

support they are seeking. In that earlier report, Fox found Spanish-dominant Internet

users are far less likely to search online for someone with similar health concerns than

English-dominant users, at six percent compared to 19% (Fox, 2011). Latinos are,

however, using the Internet significantly more to look up information on pregnancy and

childbirth, once again illustrating this variation in support (Fox, 2013).

CaringBridge, PatientsLikeMe and RareConnect: A Comparison of Three Different

Websites

Online support websites are distinct and have their own cultures and

idiosyncrasies. Yet many of their users view them as an essential tool for managing their

health and health conditions. Three excellent examples are CaringBridge,

PatientsLikeMe and RareConnect. The table contained in the Appendix offers a

comparison perspective on their similarities and differences.

There is much that health care professionals can learn from them. For example, in

her 2011 report, Fox found that patients with rare diseases have an overwhelming need to

connect with others with similar conditions, in attempts to extend their network and tap

into collective knowledge (Fox, 2011). A website like RareConnect can facilitate this. If

health care providers and nurses recognize this need, they can better support their patients by helping steer them to RareConnect or similar sites.

Recommendations for Nurse Educators

Peer-to-peer online health support is a fairly new phenomenon and the health care industrial complex is still in the initial stages of learning how to work with it. Research studies up to now have consisted of relatively small samples with publication limited to a handful of peer-reviewed journals, limiting or preventing any generalizations that can be made about their findings. These studies do give the impression, however, that patients are continuing to connect and network over health issues, much as they do for social or career outlets. Some sites can be quite complex and difficult to navigate, so initial nursing assistance may be appreciated. Patient education is a major concern of nurses and nurse educators and so this topic is timely and should appeal to the profession. The five following recommendations arose out of examination of this subject and represent a synthesis of analysis and applicability.

Recommendation 1: Nurse Educators need to familiarize themselves with these websites

Nurse educators should consider online support communities for use as a potential tool in their patient education toolbox. In the restructured health care of today, patient visits can be limited and prescriptive due to billing realities. As Hoch and Ferguson point out, "…even though there may now be less time for the counseling, storytelling, support, information sharing, and empowerment-based training that was once a routine part of the typical office visit, we can now help our patients obtain such services by referring them

to online patient networks," (Hoch & Ferguson, 2005, p. 0730). In a 2011 article, the

American Academy of Pediatrics urged pediatricians to broaden their digital technology

knowledge, "so that they can have a more educated frame of reference for the tools their

patients and families are using," (O'Keeffe, Clarke-Pearson, & the Council on

Communications and Media, 2011, p. 803). A nurse can therefore refer a patient to a

resource website like PatientsLikeMe, but the nurse should be educated and familiar with

the site.

　　　Nurses need to become aware of what online support opportunities exist for a

particular health condition, then become familiar with those websites. For example, it

would be instructive for a nurse in a neurology clinic or in a hospital neurology unit to

become familiar with BrainTalk. BrainTalk is a site that hosts over 300 free online

communities for people with neurological conditions (Hoch & Ferguson, 2005). Many

websites have various tabs and links that serve a multitude of functions. PatientsLikeMe,

for example, has very extensive information on medication side effects, along with

various first-hand accounts that are cross-referenced. Users, such as the elderly, may

need assistance to become acquainted with the site and find where the most helpful

features are located.

　　　If nurses can become aware of what options exist and become familiar with them,

they may be in a better position to match patients with websites that best suit their

eHealth literacy. Norman and Skinner 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," (Norman & Skinner,

2006). They also should be able to tell patients if the sites are mobile device friendly.

Recommendation 2: Patients have been underestimated in their ability to interpret

online data but they should be educated on becoming more website savvy

There is a perception held by many health care providers that a lot of the health

information found online is misinformation and that consumers lack the ability to

distinguish good information from bad. The latest Pew report on health and the Internet

reports that as of September 2012, U.S. adult Internet use was at 81%. Out of that 81%,

72% reported using the Internet to look up health information, and 77% of those online

health seekers used a general search engine, such as Google or Yahoo (Fox, 2013). In

addition, 30% of Internet users have consulted online reviews or rankings of health care

services or treatments (Fox, 2013). People are engaging in what James Surowiecki

referred to as "the wisdom of crowds," (Surowiecki, 2004). This is similar to the concept

of crowdsourcing, whereby people attempt to tap into collective knowledge to solve a

problem. In terms of health care, people use Internet crowdsourcing tools such as blogs,

social networking sites, and support groups to get feedback on "second opinions on

diagnosis, options for treatment, experiences with providers," (Lober & Flowers, 2011, p.

177).

Although it's true that there is some questionable material online, providers

should not underestimate their patients' judgment. Fox found in her 2010 national

telephone surveys for the Pew Internet Research Center that people, even those with rare

and/or chronic conditions tend to turn to health professionals for diagnoses or

confirmation of diagnoses and other types of technical issues related to health issues.

However, in situations involving more personal, day-to-day coping or quick relief issues,

patients most preferred non-professionals. Fox dismisses the notion that patients are

using the Internet to self-diagnose and self-medicate without consulting professionals,

suggesting "advice from peers is a supplement to what a doctor or nurse may have to say

about a health situation that arises," (Fox, 2011).

What nurse educators can provide is patient education on analysis and evaluation

of websites and online communities to improve health information literacy. They can

provide patients with a list of guidelines when considering whether to join an online

support group. In participating with these online communities, patients need to ask

questions and become media savvy before sharing their personal health information

online. Nurses can assist patients in determining if websites are trustworthy.

Recommendation 3: Nurse Educators Need to Participate in the Design and

Implementation of Online Support Websites for Cultural Inclusivity

This paper pointed out earlier that some online support websites, such as

CaringBridge, tend to be homogeneous, while other studies have found a lack of

participation in online breast cancer support groups from African-Americans. This is not

to say, however, that ethnic minorities do not use the Internet for health information.

What researchers are finding is that some groups are using their mobile devices to go

online to search; some prefer to text; some are more interested in support and information

in certain areas such as pregnancy, than in managing chronic illness.

One essential consideration for nurses is to meet your various populations where

they are. An example of this can be seen in the innovative steps the Alameda County

Public Health Department has taken in engaging their county's diverse populations in

parenting and preventing teen pregnancy. Alameda County has created two programs

with social media web pages, iPOPMom and La Vida es Mia. iPOPMom is an outgrowth

of the county's Healthy Start program, Improving Pregnancy Outcomes. The county

created a Facebook page for this group, to function not as a marketing page but as a

consumer page. It is an interactive forum, which facilitates the posting of upcoming

events and relevant articles, offering social support as well as a means of facilitating

communication between the county and its clients. La Vida es Mia is a campaign housed

within Alameda County's Project HOPE program and was established as a resource to

provide Latinas with information about sex, pregnancy, health and life advice. The

county created a Facebook avatar, as a platform for posting videos and qualitative

comments and has branched out to Twitter as well.

These are examples where a population's needs were assessed and online supports

were created in a form they would find most useful. This involves not only knowing

what areas theses populations would consider online support for (e.g., parenting rather

than handling cancer) but what constitutes ease of use depending on how one accesses the

Internet. Facebook has a mobile device application that makes it easy to use on a cell

phone, whereas other websites can be cumbersome and difficult to read on a phone.

Nurse educators, with their training in inclusivity and knowledge in developing

curriculum and educational resources, need to be involved in development and design of

more programs like the ones established by Alameda County.

Recommendation 4: Nurse educators need to conduct further research on this

emerging field of study

It has only been in the last 10-15 years that peer-to-peer online support has existed

and as such, it is an area of study still in its infancy. As stated earlier in this paper, there

is a dearth of quality research that examines this phenomenon. As health care is reformed

in this country, delivery of care and coordination will evolve as well, along with the roles

of nurses and nurse educators. Nurse educators need to consider these online support

communities as a new and powerful care delivery tool and resource. However, in order

to best serve patients, a number of questions need to be analyzed through research. Large

scale, longitudinal studies are needed before any generalizations can be made; however,

with technology continually evolving, longitudinal studies could be problematic. The

public's usage patterns of today may be significantly different in five years' time, due to

technological innovation or changing public website preferences. Do usage patterns

change due to attitude or do they change due to changes in technology? Also, different

types of research should be employed, including quantitative, qualitative, and mixed

methodologies. Different populations also need to be studied to better understand use

patterns and preferences. To determine if peer-to-peer online support is efficacious, the

research will need to do a better job in analysis of outcomes, measured through such

things as patient satisfaction, perceived stress level, or improvement of symptoms.

Conclusion

Health care today is a far different cry from what existed just 15 years ago.

Technological advances and the business of health care have radically transformed the

institution. The Internet has facilitated the creation of e-Health and e-Patients, thereby

fostering participatory medicine, and changing the ways patients and providers

communicate. Providers are also no longer able to spend as much time as they'd like

with patients in discussing how they are coping, due to tight clinic schedules and billing

constraints. In addition, patients are also being discharged from the hospital much earlier

than they formerly were. These forces, along with others, have prompted a growth in online support communities but there are questions that remain around these groups.

Online support groups and the websites of today can provide support around-the-clock, as well as globally. Although nurses provide a tremendous amount of patient education, patients and their families have historically learned from and been supported by peers, often in ways that providers cannot offer. Research results that demonstrate participation in online support communities leads to better health outcomes however are still needed.

The challenge faced by nurse educators is how to best support patients with these types of web-based healthcare information resources and communities. Nurse educators should bear in mind that patients are often looking for a different type of support when they participate in online communities. Patients are looking for what it is like to live with a health condition and how to live life day-to-day with it, rather than the more technical aspects that they typically turn to health care providers for (Fox, 2011). Nurse educators have a role in these communities that still needs to be defined. The role may be as simple as acting as a guide by making patients aware of these websites, teaching them how to navigate through their intricacies, and helping them determine what online community can best meet their individual needs. Other nursing educator roles could include acting as consultants in website design or moderators in an online forum. One certainty abounds, as innovation transforms how health care takes place in today's society, nurse educators will need to continue to be innovative in their role as well.

References

Alameda County Public Health Department (n.d.). Improving pregnancy outcomes

   Program. Retrieved on April 29, 2013, from http://www.acphd.org/ipop.aspx

Alameda County Public Health Department (n.d.). Resources. Retrieved on

   April 28, 2013, from http://www.acphd.org/project-hope/resources.aspx

Anderson, I.K. (2011). The uses and gratifications of online care pages: A study of

   CaringBridge. *Health Communications, 26*(6), 546-559.

   doi: 10.1080/10410236.2011.558335

Bastable, S.B. (2008). *Nurse as Educator* (3rd ed.). Sudbury, MA: Jones and Barlett

   Publishers.

Cain, M., Sarasohn-Kahn, J., & Wayne, J.C. (2000). Health e-people: The online

   consumer experience. Institute for the Future. Retrieved on April 17, 2013,

   from the California Healthcare Foundation website:

   http://www.chcf.org/publications/2000/08/health-epeople-the-online-

   consumer-experience

CaringBridge (2012). *2012 Annual Report.* Retrieved on April 24,2013, from

   http://www.caringbridge.org/csr_docs/caringbridge_annualreport_2012.pdf

Community. (2004). In *The Merriam-Webster Dictionary* (11th ed.). Springfield, MA:

   Merriam-Webster, Inc.

deBronkart, D. (2013). About Dave. Retrieved on April 17, 2013, from

   http://epatientdave.com/about-dave/#.UW7i8xmkCS4

Eckler, P., Worsowicz, G., & Rayburn, J.W. (2010). Social media and health care: An

   overview. *PM&R, 2*, 1046-1050.

Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet Research, 3*(2). doi:10.2196/jmir.3.2.e20

Ferguson, T. (2008). *E-patients: How they can help us heal healthcare.* Retrieved February 24, 2013, from e-patients.net/

Fogel, J., Ribisl, K.M., Morgan, P.D., Humphreys, K., & Lyons, E.J. (2008). The underrepresentation of African Americans in online cancer support groups. *Journal of the National Medical Association, 100*(6), 705-712.

Fox, S. (2011). *Peer-to-peer healthcare*. Retrieved on January 26, 2013, from Pew Pew Research Center's Internet and American Life Project website: http://pewinternet.org/Reports/2011/P2PHealthcare.aspx

Fox, S. & Duggan, M. (2013). *Health online 2013.* Retrieved on February 10, 2013, from Pew Research Center's Internet and American Life Project website: www.pewinternet.org/topics/Health.aspx

Gallant, L.M., Irizarry, C., Boone, G., & Kreps, G.L. (2011). Promoting participatory medicine with social media: New media applications on hospital websites that enhance health education and e-patients' voices. *Journal of Participatory Medicine, 3*. Retrieved on January 31, 2013, from http://www.jopm.org/ evidence/research/2011/10/31/promoting-participatory-medicine-with-social-media-new-media-applications-on-hospital-websites-that-enhance-health-education-and-e-patients-voices/

Griffiths, K.M., Calear, A.L., & Banfield, M. (2009). Systemic review on Internet support groups (ISGs) and depression: Do ISGs reduce depressive symptoms? *Journal of Medical Internet Research, 11*(3). doi: 10.2196/jmir.1270

Hoch, D. & Ferguson, T. (2005) What I've Learned from E-Patients. PLoS Med 2(8):

e206. doi:10.1371/journal.pmed.0020206

Hughes, S. & Cohen, D. (2011). Can online consumers contribute to drug knowledge?

A mixed-methods comparison of consumer-generated and professionally

controlled psychotropic medication on the Internet. *Journal of Medical Internet*

Research, 13(3). doi: 10.2196/jmir.1716

Lober, W.B. & Flowers, J.L. (2011). Consumer empowerment in health care amid the

Internet and social media. *Seminars in Oncology Nursing*, *27*(3). doi: 10.1016/j.

soncn.2011.04.002

MUMS National Parent-to-Parent Network (n.d.). Retrieved on April 14, 2013, from

http://www.netnet.net/mums/index.htm

Nelson, R., Joos, I, & Wolf, D. (2013). *Social Media for Nurses: Educating Practitioners*

and Patients in a Networked World. New York: Springer Publishing Company.

Norman, C.D. & Skinner, H.A. (2006). eHealth literacy: Essential skills for consumer

Health in a networked world. *The Journal of Medical Internet Research, 8*(2).

doi: 10.2196/jmir.8.2.e9

O'Keeffe, G.S., Clarke-Pearson, K., & the Council on Communications and Media

(2011). The impact of social media on children, adolescents, and families.

Pediatrics, 127(4). doi: 10.1542/peds.2011-0054.

O'Reilly, T. (2005). *What is web 2.0?* Retrieved on April 16, 2013, from

http://oreilly.com/pub/a/web2/archive/what-is-web-20.html

Porter, C. (2004). A typology of virtual communities: A multi-disciplinary foundation

for future research. *Journal of Computer-Mediated Communication, 10*(1).

Retrieved on April 15, 2013, from

http://jcmc.indiana.edu/vol10/issue1/porter.html

Rodgers, S. & Chen, Q. (2005). Internet community group participation: Pyschosocial

benefits for women with breast cancer. *Journal of Computer-Mediated

Communication, 10*(4). Retrieved on April 12, 2013, from

http://jcmc.indiana.edu/vol10/issue4/rodgers.html

Rogers, E. (1995). Retrieved on February 10, 2013, from http://www.utwente.nl/cw

/theorieenoverzicht/Theory%20Clusters/Communication%20and%20

Information%20Technology/Diffusion_of_Innovations_Theory.doc/

Surowiecki, J. (2004). *The Wisdom of Crowds*. New York: Doubleday.

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., Bradley, R., &

Heywood, J. (2010). Sharing health data for better outcomes on PatientsLikeMe.

Journal of Medical Internet Research, 12(2). doi: 10.2196/jmir.1549

Appendix

Website	Year Founded	Services/Features	Terms of Use	Benefits to use	Disadvantages	Visitor Access
CaringBridge	1997 Non-profit	Provides personalized web pages those going through adoption, hospitalization, pregnancy, military service. Includes photo gallery, authors' journal & guestbook for visitors to read & post messages; also offers support planner	Free	• Allows families to communicate to loved ones and keep them updated during challenging times, while receiving support in turn • Personal data protected & not sold; no advertising • Authors may request names & emails of visitors to site	• Visitors unable to interact with each other • No anonymity, visitors must sign in	Access limitations imposed
PatientsLikeMe	2004 For-profit	Provides platform for patients to share health info to help manage their conditions. Users are able to connect with others with similar conditions and review, post on treatments, medications, etc.	Free	• Organization has in-house research dept & uses data to explore new treatments, cures, etc. • Extensive aggregated data on medication, symptoms & side effects • Advocacy work • No advertising	• Health info. shared with 3rd party partners, which can incl. pharm. & med. device companies • Site does not guarantee identity of members, risk of employers, insurance co. accessing shared data	Visitor access allowed; members can manipulate privacy settings
RareConnect	2009 Non-profit	Similar to PLM, provides online com. platform for users to search for others with similar diagnoses, participate in moderated online forums, share experiences & learn from peers and professionals	Free; open to patients, health profess., families, loved ones	• Allows members to dialog with others worldwide and tell their story & learn day-to-day of living with health disorder • Confidentiality through distance; no sharing with 3rd parties w/o consent • Info. on latest research & treatments	• Identity of members not guaranteed • If user posting is included in the response of another participant, orig. posting cannot be removed & is permanently archived in online community	Visitor access allowed; must be registered member to participate in online forums