How will Internet Use Affect the Patient? A Review of Computer Network and Closed Internet-based System Studies and the Implications in Understanding How the Use of the Internet Affects Patient Populations
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How will Internet Use Affect the Patient? A Review of Computer Network and Closed Internet-based System Studies and the Implications in Understanding How the Use of the Internet Affects Patient Populations

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Abstract
The widespread use of the Internet by patients is transforming the delivery of health information. Little research has been done, however, to assess the relationship between patients’ use of online health resources and self efficacy, behavior or health status. To understand these effects and create a national research agenda, professionals should establish theoretically based studies. This article provides an overview of studies using computer networks and Internet-based closed systems in which a specific population has access to online health tools similar to those available on the Internet. These studies provide a microcosm of the effects Internet use may have on a patient’s health-related behaviors. Three areas of proposed research will be explored: content research; process research; and outcomes research.

Keywords
computer networks, health behavior, Internet
THE INTERNET is transforming many aspects of contemporary life, especially in the ways people are accessing health information. Networked computers now allow e-patients to connect with other patients—as well as health professionals—around the world, providing access to medical information that until recently was reserved for academicians and professionals only, and making it possible for lay people to gain extensive insights into their own health.

The Internet and the World Wide Web allow anyone with access to a computer the opportunity to be a researcher, to scan and look through literally millions of sources of information. Growing numbers of e-patients are incorporating the online world into their daily lives. Since 1998, the number of households with computers in the USA increased 34 percent, from 42.1 percent to 56.5 percent, and the share of those households with Internet access has increased from 26.2 percent to 50.5 percent (United States Department of Commerce (USDC), 2002). The latest USDC report demonstrates the continued increase of computer and Internet usage, with almost 66 percent of the US population now using computers from any location and more than half the nation currently online (USDC, 2002). Online access has also increased dramatically. America Online, the largest Internet service provider, increased membership from 9 million in 1996 to 22.4 million in 1999 (Miller, 1998) and 27.7 million in 2001 (ISP-Planet, 2002). Other online portals can also boast large memberships, such as MSN (8 million users), United Online (5.6 million users) and Earthlink (4.8 million) (ISP-Planet, 2002). A few additional statistics also show this increase in use:

- Internet users have increased from 84 million in 1998 to 143 million in September 2001 (USDC, 2002).
- In March 2002, Internet users go online an average of seven times per week and visit 20 different sites. They spend over 33 minutes per session and in total spend over 3.46 hours browsing the Internet each week (Nielsen/Net Ratings, 2002).

The fact that consumers now have the same medical information that is currently available to providers has significant implications for the relationship between patient and provider. It alters the ways patients and providers communicate, and is helping to create a new consumer base of power in health policy and decision making. The Internet is also likely to shape personal perceptions of health and illness, patients’ compliance to treatment protocols and ultimately, overall health. The Science Panel on Interactive Communication and Health (SciPICH) concluded that ‘few other health-related interventions have the potential of interactive health communications to simultaneously improve health outcomes, decrease health care costs, and enhance consumer satisfaction’ (Eng et al., 1999).

Recent surveys seem to support this thesis. The American Internet User Survey, conducted twice a year by the Internet research company Cyberdialogue, found that the number of people retrieving health and medical information on the Internet has increased from 7.8 million in 1996 to 23.3 million in 1999 (Miller & Reents, 1998). According to the Pew Internet and American Life Project, in 2000 that number increased to 52 million, 55 percent of all Americans with Internet access (Fox & Rainie, 2000). A recent Harris poll puts the number at 100 million in 2001 and reports that 75 percent of all adults online now use the Internet to look for health care information (Harris Interactive, 2001). The latest USDC report (2002) shows that only online shopping, retrieval of news/weather and searching for product or service information surpassed retrieval of health information. Consequently, e-patients say they feel empowered by having the information because it allows them to ask their doctors well-informed questions. In the Internet User Survey, 70 percent of health information retrievers agreed that the Internet empowered them to make better choices in their lives—compared to 55 percent of non-retrievers. In the ‘Health care and the Internet’ survey, 47 percent of respondents said that the information they found on the Internet affected the decisions they made about health treatment or care (Fox & Rainie, 2000). In addition, more than 40 percent of the respondents said that the health information they had found on the Internet affected their decisions about whether they should go to the doctor, how to treat an illness or how to question their physician. Almost half also say...
that the information has improved the way they take care of themselves and 55 percent report that it improves the way they get health information (Fox & Rainie, 2000).

That people are accessing Internet health information and acting on the information they find is not in question. What effect that use has on users, however, is just beginning to be researched empirically. Despite this new research, however, there is no substantive national research agenda. Those in the fields of Health Psychology, Health Education, Health Communication and Public Health should establish an agenda that provides empirical evidence on the effects of these new resources as a means to provide positive health messages. To date, most research within the area of interactive health communication has been atheoretical due to its newness and unknown properties as a form of health information and education. There are a number of theories, however, that could be considered when evaluating current knowledge of the effects of interactive technology on health behavior, including Diffusion of Innovation Theory (Rogers, 1995), Patient-Provider Communication Theory (Roter & Hall, 1997), Social Networks and Social Support Theory (Heaney & Israel, 1997), Social Cognitive Theory and Self-efficacy Theory (Bandura, 1995). Theoretical constructs of patient behavior, patient-provider interaction, roles of social networks and social support, achieving mastery and increasing self-efficacy are all important to use in a research agenda that will bring together research findings and established health behavior theory. Because little research currently exists, however, the relationships to these theoretical constructs are only speculative.

To establish this national agenda, professionals should first become aware of the scope of the emerging field of consumer health informatics as it exists today, understanding current research findings in the areas of the use of small computer networks that link specific patient populations and an iteration of this, Internet-based closed systems designed for specific patient populations. This is important because there is currently little published research on the unfettered use of Internet health information by patients. This article provides a review of published studies to present an overview of what has been done in the area of new media and health education and how these studies can be applied to understanding how the use of the larger Internet might affect consumers not bounded by being part of a study population. Suggestions for further types of research are also explored. This type of review has not been previously published and can provide those thinking of doing Internet research with an understanding of how past studies can inform on the possible effects unsolicited patient Internet use might have on a general population. This analysis is important so that researchers can not only begin to study consumer Internet use but they can begin to design beneficial and meaningful programs that can go beyond just providing information to affect health behavior.

Use of computer technology in health education

Aecdotal reports suggest that patients are coming to doctors’ offices with reams of computer printouts, armed with information on their conditions and the latest avenues to treat them. According to Ferguson (1998) many physicians now report that a third or more of their patients are asking them about health information they have found on the Internet. It is also clear that patients are finding each other on the Internet, giving each other advice, steering each other to specialists and providing encouragement to ask questions of their doctors (Ferguson, 2000, 2002b; Harvey-Berino, Pintauro, & Gold, 2002; Hoch, Norris, Lester, & Marcus, 1999; Kramish Campbell, M eier, Carr, E nga, J ames, Reedy, & Zheng, 2001; M cKay, K ing, E akin, S eeley, & Glasgow, 2001; Woodruff, Edwards, Conway, & E lliott, 2001). What is not known, however, is whether having access to this information or networking with others is having an impact on the ways patients relate to their health care providers, make decisions about their own health care and provide support and care for other patients. There are some indications that all of these effects are occurring, mostly through methodological cues found when looking at the adoption and use of computer technology within smaller patient populations. The field of Health Education, for instance, has begun to experiment with new technologies to assess the effectiveness of interactive technology in providing health information, including
computer-generated programs, computer networks, Internet-based closed systems and electronic mail or electronic reminders of medical appointments. These new types of health education use computer-based media that enables users to access information and services, control how the information is presented and respond to information and messages (Street & Rimal, 1997). Eng & Gustafson (1999) defines ‘interactive health communication’ as the interaction of an individual with or through an electronic device or communication technology to convey health information, support decision making or influence health behaviors.

Though still not widely researched, it is in this area that methodological issues regarding use of the Internet can be better addressed. The earliest studies included health promotion in the field of nursing, including ‘Balance’, a computer-driven program created to plan balanced diets (Clark & Ellis, 1982), through the use of free standing, special purpose computers. Other early systems have used telephone lines and computer hardware to make links between two or more locations, such as the ‘Electronic Grandparent’ program which linked nursing homes to day care centers (Kerr & Hiltz, 1982) and ‘SeniorNet’, which allowed seniors to interact with each other from home (Greenberger & Puffer, 1989).

Since these early studies, computer technology has continued to improve and the use of computers in health education and health promotion has expanded. For the scope of this article, two types of uses of interactive media were examined. The first type of study examined use intranets in which computers network to other people, similar to the Internet. Like the Internet, computer networks can reach multiple users, allow interaction between users and use tailored messages that correspond to user need (Smyth & Harris, 1993). A computer network is a closed system, however, in which users are only connected to each other and to a central computer that provides users with the services of the system. The second type of study reviewed uses closed Internet-based systems to provide a population support and access to information. Similar to computer networks, these Internet-based systems are only for specific patient populations, the difference is that they access the program through the Internet and a specific website and not through a smaller intranet.

All studies reviewed in this article were published in peer-reviewed journals and abstracted by major databases for health and medical publications such as www.pubmed.gov, Medline and PSYCHLIT. Studies that have not been abstracted in these databases were excluded from review. Studies were also only reviewed if they offered a number of different experiences for users, including information, access to health care providers and access to other study participants, which simulate the types of experiences a consumer would have on the Internet. In addition, all studies included in this review conducted some type of analysis on the effects or relationships of use of computers or Internet systems on users. Descriptive studies that did not test differences in knowledge, behavior or health outcomes were not included. For instance, a few studies have been published that chronicle the use of the larger Internet by specific patient populations (Beall, Golladay, Greenfield, Hensinger, & Biermann, 2002; Duffy, Mclernen, D’Orsogna, Reagan, Spry, Joseph, & Elsahle, 2000; Hellawell, Turner, Le Monnier, & Brewster, 2000; Ikemba, Kozinetz, Feltes, Fraser, Mckenzie, Shah, & Mott, 2002; Kalichman, Weinhardt, Benotsch, DiFonzo, Luke, Austin, 2002; O’Connor & Johanson, 2000; Taylor, Aiman, & Manchester, 2001; Weissman, Gotlieb, Ward, Greenblatt, & Casper, 2000). These are descriptive studies that show how populations are utilizing the Internet and whether one can predict use of the Internet by looking at socio-demographic variables. Though interesting, they do not elucidate the effects that might occur when people use Internet health information and for that reason have not been included in the analysis.

Review of computer network and closed Internet-based system studies

To date only 11 studies have been published on the use of computer networks and four using closed Internet-based systems within specific disease populations (see Table 1). These studies deal with a variety of different patient populations, from people with HIV to caregivers of Alzheimer’s patients, and all for the same purpose—to provide a way for people to connect with other people in the same situation.
Table 1. Studies on the use of computer networks (CN) or Internet systems (IS) in health education

<table>
<thead>
<tr>
<th>Authors</th>
<th>Topic</th>
<th>Design</th>
<th>Results</th>
<th>CN/IS Better?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alemi, Stephens, Rajshelkar, Dyches, Butts, &amp; Ghadira (1996)</td>
<td>Drug use in pregnant women</td>
<td>CN vs. control</td>
<td>CN 1.5 times more likely to be in drug treatment</td>
<td>Mixed</td>
</tr>
<tr>
<td>Butts, &amp; Ghadira (1996)</td>
<td>Caring for persons with Alzheimer’s</td>
<td>CN vs. control</td>
<td>Greater confidence in decision making</td>
<td>Mixed</td>
</tr>
<tr>
<td>Dunham, Hurshman, Litwin, Gusella, Ellsworth, &amp; Dodd (1998)</td>
<td>Single young mothers</td>
<td>Descriptive of CN</td>
<td>Decreased feelings of social isolation</td>
<td>NA—not compared</td>
</tr>
<tr>
<td>Fernsler &amp; Manchester (1997)</td>
<td>Cancer patients</td>
<td>Descriptive of CN</td>
<td>Decreased parenting stress</td>
<td>NA—not compared</td>
</tr>
<tr>
<td>Flatley-Brennan (1996); Flatley-Brennan, &amp; Ripich (1994)</td>
<td>People with AIDS</td>
<td>CN vs. control</td>
<td>Decreased social isolation</td>
<td>Yes</td>
</tr>
<tr>
<td>Gustafson, Hawkins, Bobberg, Pingree, Serlin, Graziano, &amp; Chang (1999)</td>
<td>People with HIV/AIDS</td>
<td>CN vs. control</td>
<td>Improved decision-making confidence</td>
<td>Yes</td>
</tr>
<tr>
<td>Gustafson et al. (1994)</td>
<td>People living with HIV/AIDS</td>
<td>CN vs. control</td>
<td>Increased quality of life</td>
<td>Yes</td>
</tr>
<tr>
<td>Johnson, Ravert, &amp; Everton (2001)</td>
<td>Teens with cystic fibrosis</td>
<td>Descriptive</td>
<td>Heavy use of CN by experimental group</td>
<td>Yes</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>Improved quality of life</td>
<td>Yes</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Reduction of health care costs</td>
<td>Yes</td>
</tr>
<tr>
<td>Gustafson, Wise, McTavish, &amp; Taylor (1993)</td>
<td>Breast cancer patients</td>
<td>CN vs. control</td>
<td>Increased knowledge in network group</td>
<td>Yes</td>
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<td></td>
<td></td>
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<td>and higher empowerment scores</td>
<td>Yes</td>
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<td></td>
<td></td>
<td></td>
<td>All teens accessed program and reported contacting other teens in the group</td>
<td>NA—not compared</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Significant increase in perceptions of support from peers</td>
<td>NA—not compared</td>
</tr>
<tr>
<td>Authors</td>
<td>Topic</td>
<td>Design</td>
<td>Results</td>
<td>CN/IS Better?</td>
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<tr>
<td>McKay, King, Eakin, Seeley, &amp;</td>
<td>Sedentary adults with type 2 diabetes</td>
<td>IS with tailored information and personal ‘coaching’ vs. IS with information only</td>
<td>Greater physical activity in first group, especially for those using the system frequently. No significant differences in outcomes such as satisfaction, depression symptoms or use</td>
<td>Mixed</td>
</tr>
<tr>
<td>Glasgow (2001)</td>
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<tr>
<td>McTavish, Gustafson, Owens,</td>
<td>Breast cancer patients in underserved</td>
<td>Descriptive pilot study</td>
<td>Increased feelings of positive and decreased negative emotions. Acceptance and use in impoverished population.</td>
<td>NA—not compared</td>
</tr>
<tr>
<td>Hawkins, Pingree, Wise, Taylor,</td>
<td>populations</td>
<td></td>
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<td>&amp; A pantaku (1995)</td>
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<tr>
<td>Robinson (1989)</td>
<td>Self-care and disease prevention</td>
<td>CN vs. control</td>
<td>Decrease in Dr visits. Increase in self-efficacy to prevent STDs.</td>
<td>Yes</td>
</tr>
<tr>
<td>Schneider, Walter, &amp; O’Donnell</td>
<td>Smoking cessation</td>
<td>Comprehensive CN vs. limited CN</td>
<td>Users in comprehensive group more likely to stay in the program and have higher abstinence.</td>
<td>Yes</td>
</tr>
<tr>
<td>(1990)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Smith &amp; Weinert (2000)</td>
<td>Diabetes in rural women</td>
<td>IS vs. control</td>
<td>Increased knowledge, feelings of social support and quality of life.</td>
<td>Yes</td>
</tr>
<tr>
<td>Tate, Wing, &amp; Winett (2001)</td>
<td>Weight loss</td>
<td>IS with behavior therapy vs. IS with education only</td>
<td>Greater increase in weight loss in first group, more achieved weight loss goals. Greater decrease in waist circumference.</td>
<td>Yes</td>
</tr>
</tbody>
</table>

and to obtain health information in a way that either increases their treatment compliance or their feelings of self-efficacy in decision making. All of the studies show positive results in varying degrees.

Seven of the studies used an experimental design with random assignment to either an intervention or control group (Alemi, Stephens, Rajshekhar, Dyches, Butts, & Ghadira, 1996; Brennan, Moore, & Smyth, 1995; Flatley-Brennan, 1998; Gustafson, Hawkins, Boberg, Pingree, Graziano, & Chang, 1999; Gustafson, Wise, McTavish, & Taylor, 1993; Robinson, 1989; Smith & Weinert, 2000). Three studies used random assignments with one group exposed to a comprehensive computer network or tailored advice and another group which had a computer network or Internet access that included information only (McKay et al., 2001; Schneider, Walter, & O’Donnell, 1990; Tate, Wing, & Winett, 2001); another study had a quasi-experimental design in which one group had access to a computer bulletin board and the other group was given face-to-face group therapy (Alemi, Mosavel, Stephens, Ghadiri, Krishnaswamy, & Thakkar, 1996). The remaining four are all descriptive studies using convenience samples (Dunham, Hurshman, Litwin, Gusella, Elsworth, & Dodd, 1998; Fernsler & Manchester, 1997; Johnson, Ravert, & Everton, 2001; McTavish, Gustafson, Owens, Hawkins, Pingree, Wise, Taylor, & A pantaku, 1995). All of these studies have occurred within the last 12 years, with 12 of the 15 published in the past seven years (caregivers of people with Alzheimer’s, HIV/AIDS patients (two different studies), cancer patients, breast cancer patients, young single mothers, substance abusing pregnant women (two different studies), diabetes education with rural women, weight loss for overweight adults, adults with type 2 diabetes and teens with cystic fibrosis). The others address smoking cessation, breast cancer and college students (see Table 1).

In general, these studies offer a glimpse of how the use of the Internet might affect patients or consumers looking for health information on their own. All of them brought together people with similar conditions, and most allowed access to each other through the use of a closed system via e-mail or chat rooms. The premise of all these studies is that the use of these interpersonal tools allow people to gain not only knowledge but the ability to create ‘ownership’ over their health behavior or illness. Clearly having access to the computer network/Internet-based system increased knowledge (Fernsler & Manchester, 1997; Gustafson et al., 1993; Smith & Weinert, 2000); but these studies also show that health behavior theory constructs are valid when investigating the effects of having access to computer networks and Internet-based closed systems. For instance, using the theoretical construct of self-efficacy (Bandura, 1995), four studies showed that using the computer system significantly increased perceived feeling of confidence (Brennan et al., 1995; Flatley-Brennan, 1998; Gustafson et al., 1993; Robinson, 1989).

The Brennan et al. (1995) study showed that caregivers of people with Alzheimer’s disease reported greater confidence in decision making when having access to a computer network. Similarly but in a different population, the Robinson study (1989) showed that college students that had access to computer network health information increased their self-efficacy in their perceived ability to prevent sexually transmitted diseases. Results could also be related to Roter and Hall’s (1997) Patient-Provider Communication Theory, which posits that access to information might affect a patient’s ‘task’ behavior (asking questions, information recall, treatment compliance). This is seen in two of the studies (Gustafson et al., 1999; Robinson, 1989). In the Gustafson et al. study (1999), participants reported making significantly more phone calls to their health care providers; in the Robinson study, participants reported a decrease in the need for doctor visits. In addition, social support effects were clearly seen in a number of studies, which supports the constructs of Social Networks and Social Support Theory (Heaney & Israel, 1997). Six studies reported that access to the computer network/Internet-based system provided positive psychological effects (Dunham et al., 1998; Fernsler & Manchester, 1997; Flatley-Brennan, 1998; Johnson et al., 2001; McTavish et al., 1995; Smith & Weinert, 2000). A number of these studies showed that study participants decreased their feelings of social isolation (Dunham et al., 1998; Flatley-Brennan, 1998); increased their perceptions of having social support (Johnson et al., 2001; Smith & Weinert,
and allowed them to put their health problems in perspective (Fernsler & Manchester, 1997).

Finally, it is important to note that a majority of studies not only found that access to a computer network/Internet-based system affected behavior but that specific outcomes could be measured (Alemi et al., 1996; Gustafson et al., 1994, 1999; McKay et al., 2001; Robinson, 1989; Schneider et al., 1990; Smith & Weinert, 2000; Tate et al., 2001). For instance, in the Alemi et al. (1996) study, participants were 1.5 times more likely to be in drug treatment compared to controls. Gustafson et al. (1994, 1999) showed that participants with HIV/AIDS spent less time in ambulatory care visits and had fewer and shorter hospitalizations compared to control subjects with similar disease manifestations. The McKay et al. study (2001) showed that participants with access to not only Internet system information but tailored information and personal ‘coaching’ affected rates of physical activity compared to participants with access to information only. Tate et al. (2001) similarly showed that study participants lost more weight than controls, achieved weight loss goals more often and had a greater decrease in waist circumference.

These findings are important to consider when contemplating the effects the Internet may have on populations not part of a structured study, bounded by systems that offer only select options. To provide more insight into how computer network/Internet-based systems work, the following is a review of two of the most analyzed studies, the CHESS and Computerlink computer networks.

**CHESS**

The Comprehensive Health Enhancement Support System (CHESS) is a computer-based support system developed initially to help women cope with the diagnosis of breast cancer and has been adapted for a number of different health problems. The initial pilot use of this system occurred with women with breast cancer in the Milwaukee area. Researchers hypothesized that because people differ in the amount, type and timing of information and support they want after a breast cancer diagnosis, an information and support service must be available when and where people need it, not just at a clinic or doctor’s office. Because of this, a computer network allowing women to access information and/or support at any time could be a viable way to provide valuable support to women (Gustafson et al., 1993; Shaw, MCTavish, Hawkins, Gustafson, & Pingree, 2000).

The CHESS system contains integrated information, referral, decision and social support programs. It allows users to: talk anonymously with peers; question experts; learn where to get help and how to use it; read stories about people who have survived similar crises; read articles; monitor their health status; and get help-making decisions. This system has been used with breast cancer patients in both a suburban and urban area (Gustafson et al., 1993; MCTavish et al., 1995; Shaw et al., 2000), as well as with patients with HIV/AIDS (Gustafson et al., 1999). These studies have shown that participants utilized the program extensively and many felt empowered as a result of having information and access to others. In a study of low-income women with breast cancer who had few computer skills before the intervention, participants said they felt ‘acceptance, motivation, understanding and relief’ while using the system (defined as a score of 5 or better on a 7-point scale), and experienced low levels of negative emotions such as anger, stress, boredom, fear or sadness (defined as a score of 3 or lower on a 7-point scale). Though this group did not feel as empowered as the participants in the other breast cancer study (done with higher-income, higher-educated patients), researchers felt that the term empowerment may not have been fully understood by the participants based on their qualitative statements about the system (MCTavish et al., 1995). Another explanation could be that these women were dealing with so many other subsistence issues due to their poverty that a computer network could not make as large an impact on their feelings of empowerment. What is important about this finding, however, is that use of the Internet may have the same or similar effects for educated computer users as for those with few skills or with lower levels of education and that all populations can benefit from the medical information and resources available on the Internet.

In the CHESS study with people with HIV/AIDS (N = 204), groups were assigned to experimental and control groups. A analysis of
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Co-variance was conducted using HIV/AIDS stage and pretest level of the dependent variable as covariates. It was found that five months into the study, quality of life indicators showed that the treatment group scored significantly higher than the control group on 'active life' (p = .03), social support (p = .02) and participation in health care (p = .02) variables. Three months after the computer system was removed from participants' homes, there was still a significant difference in social support (p = .07) and participation in health care (p = .007). In the area of health care utilization, however, it was found that differences seen during the intervention were not apparent after the system was taken out of the home. For instance, during the intervention the average visit time with a health care provider (it was shorter) and the number of telephone calls (more phone calls) to a health care provider (it was shorter) and the number of hospitalizations for the control group compared to the control group. In addition, the number of hospitalizations for the control group were both significantly different (p = .009). These differences, other than the number of phone calls to providers, did not continue two months after the intervention was over (Gustafson et al., 1999). These results are important because they find a connection between the use of a computer network and utilization of health care. It could be surmised that the computer system allowed patients to better monitor their health and allowed them to self-diagnose and seek treatment of opportunistic infections due to the access they had to experts and to the electronic library. This is a key finding because it allows health educators to speculate that the use of computer networks, and perhaps the Internet, can not only help patients lessen their feelings of social isolation but that there can be positive effects on their health as well.

Computerlink

A computer highly tested computer network system has been developed at Case Western University and has been tested with people with HIV/AIDS and with caregivers of people with Alzheimer’s disease (Bass et al., 1998; Brennan et al., 1995; Flatley-Brennan, 1998). Like CHESS, the Computerlink program offers a closed computer system to a finite set of people. The program has three functional areas: an electronic encyclopedia with information on disease information; a decision support system that can lead a user through decision making; and a communications pathway which supports private e-mail, e-mail to a nurse for questions and public bulletin boards. The main difference between this computer network and others studied is that in the study with people with HIV/AIDS, it was not an entirely closed system and ran on a FreeNet where participants also had access to other Internet resources.

In the study of Alzheimer’s caregivers, researchers wanted to increase decision-making skills and lower the feelings of isolation most caregivers experience by providing a computer network. Caregivers (N = 102) were recruited from a variety of community groups and were randomly assigned to an intervention or control group. Evaluation results indicate that those in the intervention group experienced greater improvement in confidence in decision making but did not show improvement in actual decision-making skill or a decrease in perceived social isolation. Caregivers in the intervention group used the computer network frequently (over twice a week) and used the features that allowed them to communicate with others most frequently. Use of the encyclopedia accounted for one-third of all computer encounters. Focus group comments reflected the perceived positive benefit of being able to communicate with peers and professionals that provided much needed companionship and ability to share with others in similar situations.

A secondary analysis of the data published three years later expands on the primary findings. Researchers hypothesized that caregivers with heightened initial levels of stress and those with a heightened vulnerability to stress would experience greater benefits with the computer system and they would experience greater reductions in care-related strain—what they call the ‘buffering effect’. Researchers showed that this was true in some instances but not all. For instance, participation in the experiment did not seem to reduce caregiver strain for any of the participants but it did reduce ‘relationship strain’ for those experimental participants who were caretaking for their spouse (Bass et al.,
1998). The mixed results of this study should be looked at critically and understood within the context of the targeted audience. First, the study targeted not those with illness themselves but the caregivers of those with illness. That researchers found no difference in decision-making skill or feelings of isolation is not surprising when you take into account the feeling of loss of control caregivers feel over their spouses’ illness. Without personal ability to change behavior or do anything but care for a sick spouse, caregivers have to be a more difficult population to reach. This study does show that the presence of the computer network was quite helpful in increasing perceptions of ability to make decisions and the focus groups indicated that subjects found the computer network comforting.

The HIV/AIDS study was a six-month randomized trial in Cleveland with 57 people living with AIDS randomly assigned to treatment and control groups. The system remained active for 47 weeks and all participants in the treatment group used the system with a mean access count per participant of 297. The system was accessed a total of 8449 times over the intervention period. Most encounters lasted 12.5 minutes between the hours of 10 p.m. and 3 a.m. Most responded and wrote personal e-mail first and/or looked at public bulletin boards (Flatley-Brennan, 1998). Results of this study showed no statistical difference in factors such as decision confidence, decision-making skill, social isolation or health status between experimental and control groups. Using a depression index as a co-founder, however, did reveal that those using the computer network reduced their feelings of social isolation ($t = 5.7, p = .0$). It could be surmised that because this population is dealing with so many other stigmatizing issues, social isolation is inevitable and it would be difficult for a computer network to solve this key issue. In addition, it was also found that for those that used the system heavily, there was an association with greater decision-making confidence ($r^2 = .44, F = 8.13, p = .0$), compared to those that did not use the system as often (Flatley-Brennan, 1998). This is seen in other studies and seems to indicate a type of learning curve where more use of the system impacts on decision-making skills.

Recommendations for further research

The importance of these studies, it can be argued, is paramount to helping professionals begin to understand the potential power of consumer Internet use. The difference, of course, is that the use of the Internet by individual patients does not take place in a vacuum and the effect of the use of the information found will be variable, depending on ease of use, understandability of information and the ability to make a perceived valuable connection with others. In addition, patients seeking health information are often helped by a network of interpersonal resources, from friends and family to online contacts. This Internet ‘community’ needs to be understood in the context of overall effects of use. As noted above, there has been little focused research on unstructured patient use of the Internet. Reeves (2000) notes that little is known about how individuals who are ‘on their own’ use the vast, unstructured array of Internet resources. To get a better idea, we need to design research that is cognizant of the role that consumers play. As Ferguson says:

The online health revolution has come in under the radar of most professionals because it has been led not by physicians, not by dot-com entrepreneurs, and not by researchers at some secret NIH laboratory, but by millions of activist e-patients. (2002a, p. 1)

This revolution must be understood to enable professionals as well as policy makers and health care providers to best serve the consumer; to do this a national research agenda must be developed. In general, there are three areas to begin to systematically understand the process of patient Internet use and its relationship to health education: content research; process research; and outcomes research. One way to conceptualize these three areas is to think of a spectrum that ranges from global issues that are not specific to the individual, to the actual use of the Internet by people, to the effects that use has on the individual.

Content research

At one end of the spectrum would be those studies cataloguing the types of Internet health information available to consumers and trying to
ensure that the best information is available in the best way. These studies would include assessing quality of website content, establishing medical criteria for websites, creating tested and validated scales to measure content as well as studies that look at design, literacy and visual appropriateness of websites. Also included in this area would be descriptive studies on the use of websites by patient populations, i.e. how many people are accessing health information and specific sites used. It is in this end of the spectrum that the majority of studies have occurred. These studies are important but offer little in the way of clarifying how Internet health information is actually getting used and how that information is affecting the user. Probably the most pressing and least studied of these is the issue of the Internet and health literacy. Content research has shown that a majority of websites are written at a 10th grade reading level or above; to make Internet health content accessible and useful for low-literacy populations, those part of the ‘digital divide’, we must establish clear criteria for online content. This is important if we are to reach a broader audience.

Process research
Studies in the middle of the spectrum should include the actual processes people use to access Internet health information. This research would include qualitative analyses using existing usability measures and in-depth interviews that look not only at what a user might like about a website but what compels him to stop or go further when searching for information (for insight into this type of research see Eysenbach and Kohler’s (2002) usability research in Germany). Usability testing would give us key insights into the workings of a patient’s mind in understanding the motivations, perceived barriers and perceived benefits of retrieving Internet health information and how that information could be presented in the best way. There is almost no research published in this area, although there have been a few studies done with small populations. This is the most difficult research because there are currently no established usability criteria or measurements and it takes intense staff commitment and expertise to adequately address these issues. Expertise in not only health education strategies but also health communication, health psychology and technology science is required to conduct this type of research. This is a large gap in the research, however, and it is needed to understand the entire user experience.

In addition, because consumers have taken the lead in creating Internet resources, it becomes imperative to understand how ‘online self-helpers’, as Ferguson (2002) calls them, are creating ways to connect and share information with each other. For instance, consumer-created websites, online support communities, online patient helpers and other information avenues are prevalent on the Internet but have not been adequately researched or understood. Studying how consumers are using these resources, along with more traditional avenues of health information, is important to understanding the symbiotic relationships among patient, online contacts and ultimately health care provider.

Outcomes research
Finally, on the other end of the spectrum, are studies that look at the effects of the use of Internet health information on individuals. For the most part, practitioners have assumed that the use of and access to health information on the Internet is a positive experience for users and have jumped on the bandwagon designing websites and CD-ROM-based programs. They have in effect, however, put the cart before the horse by making assumptions without any clear evidence to do so. These types of studies are needed to begin to create a solid foundation to provide innovative, lasting and, more important, usable and worthwhile health education programs.

For instance, studies on how access to and use of Internet health information is affecting patient-provider communication and relationships, how newly diagnosed patients are using the Internet to make treatment decisions and whether that access has an effect on variables such as self-efficacy or behavior, and how social support from friends and family and the use of the Internet to connect with that support affects the patient and his/her decisions and health outcomes would all be new contributions to the field. These are just a few of the areas that need to be explored (for more research ideas, see Ferguson’s (2002a) report for the Robert Wood Johnson Foundation). Studies that assess whether using Internet health information actually makes a difference in user’s lives are
and quantitative. This can only be done with a solid foundation of research data, both qualitative and quantitative.

Conclusion

This article provides a clear justification for proposing research that begins to ascertain if the use of the Internet will have similar effects as closed computer networks or closed Internet-based systems on individual patients wanting to find health information for themselves. Up until now, practitioners have mostly assumed that patient use of the Internet has an effect on not only knowledge of disease but on behavior with health care providers and perhaps on perceived feelings of self-efficacy. In truth, however, we do not know if this is true. The studies reviewed in this article give us a reason to hope that this is the case. But only through significant new research will we be able to say conclusively that the Internet is a technology with vast implications. As Internet use continues to increase, it is vitally important to understand the effect of the use on people’s perceptions of health, their perceived role in the patient–doctor relationship and their abilities to cope and deal with illness.

As the method of delivery for health communication changes, the field will have to not only keep up with what the Internet has to offer the consumer but understand how it affects delivery of the message. As shown in this review, the use of computer networks/Internet systems had positive effects on knowledge, decision-making skills and perceived social isolation of users. Interactive health communication, including the Internet, will give us the ability to tailor information to the needs of the receiver almost instantly and eliminate the time it takes for information to reach the receiver almost instantly. Using the Internet, will give us the ability to tailor information to the needs of the user. By undertaking empirical research on the content, process and outcomes of the use of online health resources, we can be as effective as possible in using new technologies to provide the best and most useful support for a new generation of e-patients and to make the transition to a new kind of patient–provider relationship that may be more beneficial for the information age.

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