Patients as Information Managers: The Internet for Successful Self-Health Care & Illness Management

Gul Seckin*

Department of Sociology, University of Maryland, Baltimore County, 216 Public Policy Building, 1000 Hilltop Circle, Baltimore MD 21250, USA

Abstract: Information and communication technologies have introduced new and impressive tools for information sharing and building computer mediated knowledge repositories in a global context. With a large growth in aging population and high prevalence rates for chronic and degenerative diseases, the importance of patients as 'information managers' is gaining increased recognition by the U.S. National Institutes of Health. Successful management of most chronic health conditions involves self care on an outpatient basis. In the age of Internet, patients are able to build their adaptive coping and self-care skills by collecting information from various digital sources. This represents a significant step in modern medicine toward increased patient self-health care. Healthy People 2010 states that "the greatest opportunities for reducing health disparities are in empowering individuals to make informed health care decisions." This paper examines the current trends in the use of the Internet by health care consumers and provides a discussion on how integration of Internet information into illness management resources changes the patient role. This discussion is placed within the larger context of the U.S. health care system, which is key to determining the impact of the Internet on patient health behavior.

Keywords: Internet, health care consumerism, communication.

ADOPTING THE VIRTUAL PATIENT ROLE: CURRENT STATUS OF INTERNET USE BY HEALTH CARE CONSUMERS

Successful management of most chronic health conditions involves self care on an outpatient basis. This requires an integration of a variety of information and support resources available to consumers, and not completely relying on health care professionals [1]. Diagnosis of a life threatening illness like cancer dramatically impacts an individual's personal sense of autonomy (e.g., my life is controlled by cancer) and personal sense of competence (e.g., I have no control over my future). Accordingly, individuals build their adaptive coping strategies by collecting information from a variety of resources including family, friends, fellow patients and media outlets. As Gann [2] points out "information to enable participation in our health is important at all stages of our lives, but never more so than when we are faced with illness and become patients. Before we are able to cope with ill health and communicate with professional carers, we need a basic understanding of our bodies, how they work and the terminology used to describe them." (p.18).

Historically, medical information has not always been as easily available to patients as it is today. Patients did not have easy access to medical knowledge and were reliant on health care professionals, who were not receptive to discussing details of their treatment decisions [3]. Patients who were socialized to adopt the sick role were encouraged to be conforming and not to be too inquisitive or assertive [3, 4]. This

practice was justified due to their ownership of specialized knowledge and their clinical expertise [4]. Health care interactions were characterized by paternalism, where patients were expected to put themselves in the hands of clinicians to get well [3].

Technology has played an important role in altering the traditional notions of sick role and physician and patient interaction [2, 3]. With advances in information and communication technologies, specifically the Internet, health and medical information has become conveniently available to many health consumers [5, 6]. Nearly 17 years after the invention of the World Wide Web, the Internet has become such an integral characteristic of modern societies that it is almost unimaginable to conceive a world without it [7]. Clinicians and researchers pay particular attention to technology as a promising tool to empower patients through self health care management skills and to improve health care communication with providers. Previous research has shown that acquisition of these skills leads ultimately to better health and improved longevity of patients [5, 8].

Whitten *et al*. [5] point out that use of health web sites by patients and their caregivers has surpassed general Internet use and other online activities. Even though the digital divide continues to persist based on social class and race, six million people in the United States search the Internet for health information on an average day [9-11]. This number exceeds the daily average number of 2.27 million Americans who make visits to physician offices [12]. Finding the most recent health information is specifically critical for patients diagnosed with a life threatening illness such as cancer or HIV. By the time experimental approaches and clinical trials are published for cancer and HIV in a paper format, it might be too late for those who are willing to try them. In contrast, the

*Address correspondence to this author at the Department of Sociology, University of Maryland, Baltimore County, 216 Public Policy Building, 1000 Hilltop Circle, Baltimore MD 21250, USA; Tel: 410-455-5938; Fax: 410-455-1154 ; E-mail: gseckin@umbc.edu

leading Internet search engines index over 100,000 medical web sites. These sites provide instant access to information including reports of peer reviewed clinical trials and full-text digital links to articles.

INFORMED AND EMPOWERED ONLINE HEALTH CARE CONSUMERS AND INFORMATION SHARING

With 800 million people around the globe and nearly 80 percent of the U.S. population online, the Internet has established a virtual medical library for health consumers [12, 13]. In a study of 188 women diagnosed with breast cancer, nearly half of the respondents indicated they consulted the Internet for health information [14]. Satterlund, McCaul, and Sandgren [15] also reported that online information resources were the second most frequently cited source eight months after cancer diagnosis and the most frequently cited source sixteen months after diagnosis. Furthermore, not only the medically ill but their caregivers also use the Internet to gather information. Madden and Fox [16] reported that the Internet was the most important tool to find answers to various questions for most of the people (58%) who identified themselves as caregivers.

Credible web sites, such as those affiliated with national and academic institutions, not only provide information on acute and chronic diseases but also offer new research results, alternative treatment approaches, new medications and patient support groups [17-20]. Recent technology initiatives include integration of health web sites, such as NIH clinical trials, with various electronic products as their newest features. Today, patients have the convenience of receiving health and medical information from advanced cell phone technology while on the go. For example, a new iPhone application "Clinical Trials" allows users to access the National Institute of Health updates promising health care consumers an instant access to information. This has led some to refer to health information on Internet as 'the medical web' [21, 22].

In order to meet the increasing demand for health information on Internet, the National Library of Medicine, the National Institute of Health and the National Institute of Cancer, among others, provide online versions of their health and medical information to patients [21]. Hospital Internet Marketing Report in 2002-2003 showed that over eighty percent of hospitals use Internet applications in response to increasing consumers' expectations [5]. Many health insurance companies also design 'wellness' sites to address health questions and concerns of patients ranging from allergies to healthy food choices to cancer management. Furthermore, electronic health information on the web is not limited to simple non-interactive informational sites [20]. The internet allows information to be shared in the form of both text and images. Among the applications are online diagnostic tools where patients can enter their demographic and health information, symptoms they experience and their credit card number despite potential pitfalls of information [23].

The Internet, with its enhanced capacity for human interaction that transcends time and space barriers, has also been changing the degree and the manner in which health care consumers have contact with others for information and support [8, 9, 22, 24]. Online patient groups are one of the most popular web-based applications among health care consumers [5, 23]. The advent of technology enables people to enlarge their social nexus and form extensive social capital that can be tapped into when coping with a health problem [25-28]. Research by LaCoursiere, Knobf and McCorkle [29] reveals that nearly half of breast cancer web sites have links to online support groups. One of the reasons leading to formation of patient networks on the Internet is that these groups bring alternative perspectives where patients can compare their treatments with that of others [8, 30-32]. Patient support groups on the Internet are also places where one patient asks, many answer, and all learn [33]. This interweaving of personal experiences on the Internet through personal home pages, blogs, message boards, listserves and social networking sites such as Facebook reveals a desire for shared exploration and production of experiential knowledge. Patients do not want to be completely reliant on expert knowledge. This represents a significant turning point in acceptance and utilization of Internet technology by the general public. Patients emerge as 'digital bio-citizens' who are actively involved in their illness and health care management and feel personally responsible for achieving the best outcomes for themselves [34]. Health consumers also become influential advocates for specific treatments, research, public awareness and education campaigns as a result of shared experiential knowledge on the Internet [35, 36]. New applications of information and communication technologies are transforming the culture of medicine and patient role [20, 34]. Eysenbach [37] has referred to these changes in sick role a 'paradigm shift.'

MANAGED CARE POLICIES AND CHANGES IN SICK ROLE

Health care policies implemented through the managed care system to lower health care costs played an important role in the changes experienced in the traditional sick role and patient behavior [38, 39]. Increasing fiscal pressures in health care led to a set of political as well as socio-medical changes which affected the way medicine is practiced and changed the nature of patient and doctor interactions [40, 41]. Today, most health care consumers believe it is their responsibility to become well-informed and to be actively involved in their health care management with their providers as partners [42]. Clinicians' interactions with their patients take place under stringent constraints of time as 'productivity' expectations imposed by the managed care system force physicians to work under tighter scheduling of shorter appointments and to see as many patients as possible [20, 23, 38, 43, 44]. This leads to patient dissatisfaction with the amount and quality of information provided. As Kahana and Kahana [45] have pointed out, managed care productivity expectations limit the amount of time physicians spend with each patient. With the average time in the physician office being around 10 minutes, patients do not have enough time to address their health concerns and receive adequate answers to their questions [38]. Feeling hurried through appointments, physicians find it hard to communicate enough information to the satisfaction of their patients [38]. Research reports that inadequacy of information ranks the highest among the most frustrating aspects of health care interactions in the managed care environment [12]. Feeling hurried through appointments, patients find it difficult to remember details of their consultations [12, 46-48]. Most health care consumers believe that medical practitioners do not give

them enough information to make informed health care choices and decisions [49].

In addition, shortened length of hospital stays, limited access to specialists and emphasis on ambulatory and home health care due to restrictions on insurance coverage compel patients to leave their dependency on health care providers and assume a more proactive health care partner role in producing health [50-52]. Accordingly, most health care consumers believe it is their responsibility to become well informed and proactive. These consumers use the Internet to evaluate the health care services they receive by comparing what is available and what other patients report [53-55]. These are evidences of patient self advocacy, facilitated by Internet technology, to facilitate more informative, inclusive and proactive participation in health care interactions [56]. In other words, 'agency' becomes manifested in patients' choices of becoming more informed [57]. New understanding and practices of patient behavior also resulted from the development of health promotion movement as a public health policy approach and the contemporary emphasis on personal responsibility to achieve health, as a commodity, through personal actions [23, 41, 58].

Access to medical information is increasingly considered by middle class educated patients a necessary component of 'empowered medical discourse' as reflected in phrases like 'armed with my research' [42]. Advancements in information and communication technologies further accelerated these changes in patient culture [5, 43]. As Morahan-Martin [12] point out that as managed care and insurance restrictions limit consumers' access to institutional resources such as specialists, the Internet fills the void by providing information to consumers. Time constraints imposed on medical consultations have led to corresponding increases in online health information searching. Patients have a greater sense of responsibility toward managing personal health [23, 59, 60]. Information enables health consumers to take a proactive stance and become self-advocates. The Internet provides an effective means of being informed health care partners in interaction with health care providers [35, 61].

PERSONAL RESPONSIBILITY TO MANAGE HEALTH CARE

Consulting web health resources and collecting information on issues of concern so that one can make the best choices reveals how the general population is now exhorted to assume active responsibility to improve and maintain their health [62-64]. Obtaining information by utilizing technological resources has emerged as a personal responsibility of being healthy [64]. Health care consumers often report that being able to comprehend medical terms and information is required not only to make sense of the treatment process but to make the most of long awaited and time-limited consultations. Patients' ability to comprehend the information helps make sure that health professionals pay serious attention to their concerns in a short amount of time available [42]. This approach helps to foster informative, inclusive and respectful interactions between professionals and patients and increases the quality of the services they receive [42, 56, 65]. As previous research has established, consumers who can 'speak the same language' with doctors are more likely to be taken seriously [42]. Information is perceived as a means of obtain-

ing equality into the doctor-patient interactions [6, 66]. This information is sometimes used as a basis for reevaluation and even renegotiation of treatment approaches [56]. It is also reported that consumers use online health information resources to supplement or evaluate the accuracy of the information provided by health professionals [20]. Numerous researchers have found that consumers print off information from various health web sites and take it to the next appointment with their clinicians.

The Internet facilitates this link between becoming knowledgeable and forging alliances with professionals [41]. A survey with 10,000 patients indicates that information resources on the Internet have a positive impact on patients' communicational proficiency with their doctors. These resources help them to be better prepared for their appointments and know what questions to ask in advance. Increased patient knowledge facilitates better use of time within the medical encounter, thus enabling the physician and patient interaction to be used efficiently [12, 67].

Furthermore, most health consumers make their decisions after reading information on the Internet [12, 67-69]. A study of 375 cancer patients who used the Internet found that an overwhelming majority of the respondents (94 percent) reported an improved understanding of the nature of their disease and its treatment, 69 percent indicated better communication with their clinicians and 58 percent reported being able to make informed health care choices and decisions for themselves [70]. Numerous studies have documented a statistically significant relationship between using Internet based health information resources and better self-health care management skills, improved increased quality of life and higher levels of expectations for survival [20, 71-75].

Research with clinicians about their perceptions of patients bringing information to the medical consultations found that 520 out of 560 respondents believed that Internet-based information empowered patients and encouraged the development of shared care [76]. Health consumers arming themselves with information can help identify treatment approaches and alternatives they are more comfortable with than those chosen by the physician. Dilliway and Maudsley [77] found that over one-third of general physicians and nearly 90 percent of nurses thought that online health resources helped with patient understanding and improved physician and patient communication during health care consultations. Some patients even advocate for research on experimental treatments and engage in patient activism to change health policies and practices as a result of their access to online medical information [56]. Thus, the Internet opens up a new world of self advocacy that many had not previously considered possible [5, 33, 41, 56, 78, 79].

As patients become proactive, they become co-creators of knowledge and what Novas and Rose [80] called 'digital bio-citizens.' Medical information obtained from digital sources serves either as a substitute for or as a complement to health information provided by clinicians [29, 41, 56]. This evolution of the patient actions from the classicconceptualization of 'sick role' by Parsons [36] to patients as 'information managers' symbolizes the Internet facilitated patient empowerment [70, 74, 75].

TECHNOLOGY EMPOWERED OLDER HEALTH CARE CONSUMERS

As information and communication technologies develop at a rapid rate, aging Americans are increasingly adapting themselves to this new environment [81, 82]. Adults aged fifty five and older are the fastest growing Internet users [83, 84]. These cyberseniors face challenges of increased longevity that require adaptations in their coping skills to gain better control of their health care in managed health care environment [81, 85].

Older adults could be primary beneficiaries of Internet and gain from online information technology for several reasons: First, older adults are more in need of health and medical information due to health challenges of aging and physical decline. Second, limitations on health care utilization due to managed care and insurance encourage the use of Internet technology to compensate or complement physician provided information. Third, life transitions such as retirement may provide additional time to browse Internet to gather needed information [86]. Fourth, decline in mobility due to health problems or transportation challenges increase the importance of Internet for senior citizens. Fifth, decline in information and support network e.g., loss of spouse and friends makes Internet technology a valuable health information and support resource for older consumers. Accordingly, the Internet is a powerful tool to maintain and promote health related quality of life and well-being in old age [87].

Research has shown that health is the most searched online topic by older health consumers [83, 88]. Eighty-two percent of Americans aged 50 to 64 and 66 percent of those aged 65 and older reported using the Internet to gather information about their health conditions and services available to older adults such as Medicare and Medicaid [81, 83, 89]. Research on the use of electronic health information in primary care found that obtaining information from Internet was significantly associated with perceived ability to better cope with ill health [90]. Challenges experienced in old age such as decline in physical health may cause some older adults to feel lack of control in their lives. Using Internet technology may enhance individuals' sense of control and improve their self confidence in coping with challenges of old age [66, 91]. Proactive information seeking is also used as a coping strategy to elicit clinician responsiveness to patient questions and to facilitate informed physician-patient dialogue.

As Kahana & Kahana [45] point out, the elderly constitutes one of the main underserved groups in information provision in a clinical setting. Taha, Sharit and Czaja [92] found that most older health care consumers found information online that they were not able to obtain from their physicians. They used online health resources to get prepared before the medical appointment and to obtain a second opinion after physician visit. In other words, web resources functioned as a 'second opinion' source for many users. Gathering information pre and post medical visit was reported to give patients ability to ask questions and better understand the information provided. This, in turn, enhanced the quality of doctor-patient medical exchange [92]. Another benefit of the Internet technology for the aged is opportunity to participate in online patient information and discussion groups. Availability of these health groups on the Internet reduces isolation of older adults, connects them with other patients coping with the same health issue and enables them become an interactive participant in health discussions [66, 91]. These groups link senior adults to the vast network of information and support resources and facilitate informed health care choices [81]. As previous research has shown, online cancer support groups provide a plethora of information, which when discussed with one's health provider, can lead to better medical decision making [69].

As McMellon and Schiffman [91] state, individuals choosing to be online for health care purposes are actually empowering themselves since they are choosing to control their health through information. For example, it is important for the elderly and their caregivers that they have access to information on residential care facilities. Castle and Sonon [82] point out that several web sites such as the Assisted Living Federation of America (www.alfa.org), Assisted Living INFO (www.assistedlivinginfo.com), National Center for Assisted Living (www.ncal.org) and CareScout Network (www.carescout.com) provide important information for older health care consumers. Being able to find needed information online, such as name and location of facilities, their bed size, services and special accommodations offered and price and quality rankings (e.g., complaints on consumer web sites) can be a powerful empowerment tool for older patients [82]. Availability of such information on the Internet would allow older adults to determine the most appropriate residential care setting for themselves [82]. Several states, such as Florida, Arizona, California, Maryland, Connecticut and Mississippi already provide Internet users with such information. Most health web sites are being redesigned to reflect the needs of older health consumers and their caregivers [88]. The National Institutes of Health, the United States National Library of Medicine, the Centers for Medicare and Medicaid have also developed web sites for older health consumers and for the professionals working with them [88].

PATIENTS AS INFORMATION MANAGERS

This combination of technological resources with professional resources emerges as an important tool to promote successful illness management, health and longevity [50, 94, 95]. Active information seeking and utilization of Internet resources in order to facilitate more informative, inclusive and participatory interactions with health professionals emerge as an important strategy to promote personal health, considering patient dissatisfaction with the current health care environment under managed care policies [56, 94-96]. This self-advocacy includes making health care alliances with professionals through better communication and taking proactive actions to improve personal health care management skills [61, 97-99]. Table **1** below presents a summary of how the Internet is used as a tool to achieve optimal health management and care when coping with a chronic illness. These actions increase patient competence, facilitate development of shared care and even improve healthoutcomes [76, 100]. Patients build their adaptive coping skills by collecting information from digital health sources and feel personally responsible for achieving the best health outcomes for themselves [96]. This is increasingly considered a necessary component of 'empowered medical interactions [36]. Accordingly, clinicians and researchers see the Internet as a promising tool to empower patients through better knowl-

Table 1.   Key Uses of Internet for Successful Self-Health Care & Illness Management

To provide preliminary self-diagnosis
To self educate to comprehend medical terminology & information
To find the most up-to-date information (e.g., clinical trials, medications)
To learn new or enhance existing self health care & management skills
To compensate or supplement doctor's information
To evaluate accuracy of doctor's information
To compare treatment and evaluate health care received
To compare health status with what is written and with other people
To prepare for next doctor's appointment-Gather information in order to know what questions to ask
To obtain alternative opinion and receive feedback after doctor's visit
To share illness experience and produce experiential knowledge with other patients
To make informed health care choices and decisions

edge, enhanced self health care skills and improved communication with health professionals [5, 8].

CONCLUSIONS

With a large growth in aging population and high prevalence rates for chronic and degenerative diseases [101], the significance of patients as 'information managers' is increasingly recognized by patients, clinicians and researchers [20, 102]. Internet based information resources should be implemented as a major means of promoting patients' health and disease management skills by extending access to information to underserved populations including older adults, the poor and minority groups [66, 85].

Better informed patients enhance their communication skills, take actions to improve their health, monitor their health status and even challenge professionals to improve their health care. Patients turn their knowledge into health care management competencies [1]. Better and more informed patients also reduce health care costs through greater self-management of health behaviors and a more efficient use of health care service resources [77]. More importantly, when discussed with health care professionals, the wealth and variety of health information on Internet can improve clinical patient outcomes including increased survival and longevity [103].

Best health outcomes are achieved through partnerships between patients and providers. The expertise of health care professionals is essential for an accurate evaluation of online health information for making appropriate choices [64, 104]. Information obtained from Internet resources should be incorporated into patients' discussions with their health care providers and accuracy of information patients bring into consultations should be evaluated [39]. This suggests an active role, and even responsibility, for health care professionals. Clinicians can ask their patients whether they consult information on Internet and assist them in evaluating the information. In addition, health care professionals should be able to recommend credible medical web sites. They can promote the development of uniform standards for develop-

ment of accurate e-health sites to be utilized by health care consumers [52, 64, 105].

REFERENCES

[1]   Gustafon D, Hawkins R, McTavish F, *et al.* Internet based interactive support for cancer patients: Are integrated systems better? J Commun 2008; 58: 238-57.

[2]   Gann R. In: Aldershot RG, Ed. The health information handbook. Gower: UK 1986; pp. 18-47.

[3]   Parsons T. The social system. New York: The Free Press 1951.

[4]   Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. Soc Sci Med 1999*;* 49: 651-61.

[5]   Whitten P, Notman M, Maynard C, Henry R, Glandon R. Interactive health communication technologies in the public health sector: Positive perceptions still outpace actual utilization. J Technol Hum Serv 2004; 22: 25-40.

[6]   Anderson JG. Consumers of E-health. Patterns of use and barriers. Soc Sci Comp Rev 2004; 22: 242-8.

[7]   Barak A, Ed. Psychological aspects of cyberspace. Theory, research, applications. Cambridge: Cambridge University Press 2008.

[8]   Lee H. Implosion, virtuality, and interaction in an internet discussion group. Inf Commun Soc 2005; 8: 47-63.

[9]   Fox S, Fallows D. Internet Health Resources. Pew Internet and American Life Project 2003. Available from: http://www.pewinternet.org/Reports/2003/Internet-Health-Resources.aspx

[10] Cotton SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. Soc Sci Med 2004; 59: 1795-806.

[11] Fox S. Online Health Search. Washington, DC: Pew Internet and American Life Project 2006. Available from: http://www.pewinternet.org/ Reports/2006/Online-Health-Search-2006.aspx

[12] Morahan-Martin J. How internet users find, evaluate, and use online health information: A cross-cultural review. Cyberpsychol Behav 2004; 7: 497-510.

[13] Goetz HL, Friedman DB, Celestine A. Evaluation of a public library workshop: Teaching older adults how to search the internet for reliable cancer information. J Consum Health Internet 2006; 10: 29-43.

[14] Fogel J, Albert SM, Schnabel F, Ditkoff BA, Neugut AI. Internet use and social support in women with breast cancer. Health Psychol 2002; 21: 398-404.

[15] Satterlund MJ, McCaul KD, Sandgren AK. Information gathering over time by breast cancer patients. J Med Internet Res 2003; 5: e15.

[16] Madden M, Fox S. Finding answers online in sickness and in health. Pew Internet & American Life Project 2006. Available

from: http://www.pewinternet.org/pdfs/PIP_Health_Decisions_2006.pdf

[17] Smith L. Internet use among people with HIV/AIDS. J Technol Hum Serv 2003; 22: 17-29.

[18] Fogel J. Internet breast health information use and coping among women with breast cancer. Cyberpsychol Behav 2004; 7: 59-63.

[19] Bundorf K, Wagner HT, Singer JS, Baker CL. Who searches the Internet for health information? Health Serv Res 2006; 41: 819-36.

[20] Sillence E, Briggs P. The Oxford handbook of internet psychology. In: Joinson AD, McKenna KYA, Postmes T, Reips UD, Eds. Oxford: Oxford University Press 2007; pp. 347-59.

[21] Cullen R. Health information on the internet. A study of providers, quality, and users. Westport: Praeger 2006.

[22] Weiser BE. The functions of Internet use and their social and psychological consequences. Cyberpsychology Behav 2001; 4: 723-43.

[23] Conrad P. Medicalizaton of society. Baltimore: The John Hopkins University Press 2007.

[24] Gooden R, Winefield HR. Breast and prostate cancer online discussion boards: A thematic analysis of gender differences and similarities. J Health Psychol 2007; 12: 103-14.

[25] Tichon JG, Shapiro M. When a little help from my friends: Children, the internet and social support. J Technol Hum Serv 2003; 21: 73-92.

[26] Weiss T. Correlates of posttraumatic growth in married breast cancer survivors. J Soc Clin Psychol 2004; 23: 733-46.

[27] Macias W, Lewis SL, Smith T. Health-related message boards/chat rooms on the web: Discussion content and implications for pharmaceutical sponsorship. J Health Commun 2005; 10: 209-23.

[28] Coulson SN. Receiving social support online: An analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. Cyberpsychol Behav 2005; 8: 580-4.

[29] LaCoursiere SP, Knobf MT, McCorkle R. Cancer patients' self reported attitudes about the internet. J Med Internet Res 2005; 7: e22.

[30] Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. BMJ 2004; 328: 1166-78.

[31] Winkelman WJ, Choo CW. Provider-sponsored virtual communities for chronic patients: Improving health outcomes through organizational patient centered knowledge management. Health Expect 2003; 6: 352-8.

[32] Maly RC, Umezawa Y, Leake B, Silliman RA. Mental health outcomes in older women with breast cancer: Impact of perceived family support and adjustment. J Psychosoc Oncol 2005; 14: 535-45.

[33] Ussher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. Soc Sci Med 2006; 62: 2565-76.

[34] Rose N, Novas C. Global Assemblages: Technology, politics, and ethics as anthropological problems. In: Ong A, Collier S, Eds. Malden: Blackwell 2005.

[35] Heath D, Rapp R, Taussig K. A companion to the anthropology of politics. In: Nugent D, Vincent J, Eds. Oxford: Blackwell 2004; pp.152-67.

[36] Schaffer D, Kuczynski K, Skinner D. Producing genetic knowledge and citizenship through the internet: Mothers, pediatric genetics, and cybermedicine. Sociol Health Illn 2008; 30: 145-59.

[37] Eysenbach G. Recent advances: Consumer health informatics. BMJ 2000; 320: 1713-6.

[38] Waitzkin H. Handbook of medical sociology. In: Bird CE, Conrad P, Fremont AM, Eds. New Jersey: Prentice-Hall, Inc. 2000; pp. 271-83.

[39] Mechanic D. Mental health and social policy. Beyond managed care. Massachusetts: Allyn & Bacon 2008.

[40] Skinner D, Schaffer R. Families and genetic diagnoses in the genomic and internet age. Infant Young Child 2006; 19: 16-24.

[41] Stevenson FA, Kerr C, Murray E, Nazareth I. Information from the internet and the doctor-patient relationship: the patient perspective-a qualitative study. BMC Fam Pract 2007; 8: 47.

[42] Schaffer D, Kuczynski K, Skinner D. Producing genetic knowledge and citizenship through the internet: Mothers, pediatric genetics, and cybermedicine. Sociol Health Illn 2008; 30: 145-59.

[43] Lupton D. Medicine as culture. Thousand Oaks: Sage Publications 2006.

[44] Fox S, Rainie L. The online health care revolution: How the web helps Americans take better care of themselves. The Pew Internet & American Life Project 2000; Available from: http://www.pewinternet.org/Reports/2000/The-Online-Health-Care-Revolution.aspx

[45] Kahana E, Kahana B. Patient proactivity enhancing doctor-patient-family communication in cancer prevention and care among the aged. Patient Educ Couns 2003; 50: 67-73.

[46] Goldner M. Using the internet and email for health purposes: the impact of health status. Soc Sci Q 2006; 87: 690-710.

[47] Gattellari M, Voigt KJ, Butow PN, Tattersall MHN. When the treatment goal is not cure: Are cancer patients equipped to make informed decisions. J Clin Oncol 2002; 20 (2): 503-13.

[48] Harrison JP, Lee A. The role of e-health in the changing health care environment. Nurse Econ 2006; 24: 283-8.

[49] Carvel J. Lack of information worries NHS patients. Guardian 2005; 21 February: 10.

[50] Arora NK. Interacting with cancer patients: Significance of physicians' communication behavior. Soc Sci Med 2003; 57: 791-806.

[51] Zebrack BJ. Cancer survivor. Identity and quality of life. Cancer Pract 2000; 8: 238-42.

[52] Kahana E, Kahana B, Seçkin G. Using technology as a tool for successful aging. Paper presented at the conference on gerontechnology today and tomorrow. University of Washington 2004.

[53] Haas-Wilson D. Arrow and the information market failure in health care: The changing content and sources of health care information. J Health Polit Policy Law 2001; 26: 1031-42.

[54] Baker L, Wagner TH, Singer S, Bundorf KM. Use of the internet and E-mail for health care information. Results from a national survey. JAMA 2003; 289: 2400-6.

[55] Rice ER, Shephard A, Dutton HW, Katz EJ. The Oxford handbook of Internet psychology. In: Joinson AN, McKenna KYA, Postmes Y, Reips UD, Eds. Oxford: Oxford University Press 2007; pp. 7-30.

[56] Rogers A, Mead N. More than technology and access: Primary care patients' views on the use and non-use of health information in the internet age. Health Soc Care Commun 2004; 12: 102-10.

[57] Høybye MT, Johansen C, Tjørnhøj-Thomsen T. Online interaction, effects of storytelling in an internet breast cancer support group. Psychooncology 2005; 14: 211-20.

[58] Cockerham WC. Handbook of medical sociology. In: Bird CE, Conrad P, Freeman AE, Eds. New Jersey: Prentice-Hall, Inc. 2000; pp.159-72.

[59] Ericksen JA. Taking charge of breast cancer. Berkeley: University of California Press 2008.

[60] Klawiter M. The biopolitics of breast cancer. Minneapolis: The University of Minnesota Press 2008

[61] Kahana E, Kahana B. On being a proactive health care consumer: making an "unresponsive" system work for you. Res Soc Health Care 2001; 19: 21-44.

[62] Neuberger J. The educated patient: New challenges for the medical profession. J Intern Med 2000; 247: 6-10.

[63] Broom A. Medical specialists' accounts of the impact of internet on the doctor/patient relationship. Interdiscip J Soc Stud Health Illn Med 2005; 9: 319-38.

[64] Kivits J. Everyday health and the Internet: A mediated health perspective on health information seeking. Sociol Health Illn 2009; 31(5): 673-87.

[65] Berland KG, Elliott MN, Morales LS, *et al.* Health information on the internet. JAMA 2001; 285: 2612-21.

[66] Opalinski L. Older adults and the digital divide: Assessing results of a web-based survey. J Tech Hum Serv 2001; 18: 203-21.

[67] Williamson K. Where one size does not fit all: Understanding the needs of potential users of a portal to breast cancer knowledge online. J Health Commun 2005; 10: 567-80.

[68] Suggs SLA. 10-year retrospective of research in new technologies for health communication. J Health Commun 2006; 11: 61-74.

[69] Seçkin G. Internet technology in service of personal health care management: Patient perspective. J Tech Hum Serv 2009; 27: 79-92.

[70] Seçkin G. Role of internet technology in enhancing patient health care communication with medical professionals. Int J Technol Know Soc 2008; 4: 29-36.

[71] Cohen M. Coping and emotional distress in primary and recurrent breast cancer patients. J Clin Psychol Med Settings 2002; 9: 245-51.

[72] Wright K. Computer-mediated social support, older adults, and coping. J Commun 2000; 50(3): 100-18.

[73] Sharp JW. The Internet. Changing the way cancer survivors receive support. Cancer Pract 2000; 8(3): 145-7.

[74] Davis JJ. Disenfranchising the disabled: The inaccessibility of internet based health information. J Health Commun 2002; 7: 355-67.

[75] Reeves PM. Coping in cyberspace: The impact of internet use on the ability of HIV-positive individuals to deal with their illness. J Health Commun 2000; 5: 47-59.

[76] Cox B. The impact of the internet on the GP-patient relationship. Inform Prim Care 2002; 1095-8.

[77] Dilliway G, Maudsley G. Patients bringing information to primary care consultations: A cross-sectional (questionnaire) study of doctors' and nurses' views of its impact. J Eval Clin Pract 2008; 14: 545-7.

[78] Stevenson F, Scambler G. The relationship between medicine and the public: the challenge of concordance. Health 2005; 9(1): 5-21.

[79] Rier AD. Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. Sociol Health Illn 2007; 29: 1043-58.

[80] Novas C, Rose N. Genetic risk and the birth of the somatic individual. Econ Soc 2000; 29: 485-513.

[81] Stark-Wroblewski K, Edelbaum JK, Ryan JJ. Senior citizens who use E-mail. Educ Gerontol 2007; 33: 293-307.

[82] Castle NG, Sonon KE. Internet resources and searching for a residential care setting: What information is available for consumers? J Appl Gerontol 2006; 25: 214-33.

[83] Hoffman-Goetz L, Friedman DB, Celestine A. Evaluation of a public library workshop: teaching older adults how to search the internet for reliable cancer information. J Consum Health Internet 2006; 10: 29-43.

[84] National Telecommunications and Information Administration. Falling through the net: Toward digital inclusion. Washington, DC: United States Department of Commerce 2006. Available from: http://www.ntia.doc.gov/ntiahome/fttn00/contents00.html

[85] Blit-Cohen E, Litwin H. Elder participation in cyberspace: A qualitative analysis of Israeli retirees. Aging Stud 2004; 18: 385-98.

[86] Smith-Wagner L, Wagner TH. The effect of age on the use of health and self-care information: Confronting the stereotype. Gerontologist 2003; 43: 318-24.

[87] Bryant LL, Altpeter M, Whitelaw NA. Evaluation of health promotion programs for older adults: An introduction. J Appl Gerontol 2006; 25: 197-213.

[88] Morgan R. Technology greets the age wave. Gerontologist 2005; 45: 704-10.

[89] Gackenbach J, Stackelberg von H. Self online. In: Gackenbach J, Ed. Psychology and the internet: intrapersonal, interpersonal, and transpersonal implications. Burlington: Academic Press 2007; pp. 55-73.

[90] Godfrey M, Johnson O. Digital circles of support: meeting the information needs of older adults. Comput Hum Behav 2008; 25: 633-42.

[91] McMellon CA, Schiffman LG. Cybersenior empowerment: How some older individuals are taking control of their lives. J Gerontol 2002; 21: 157-75.

[92] Taha J, Sharit J, Czaja S. Use of and satisfaction with sources of health information among older internet users and nonusers. Gerontologist 2009; 49: 663-73.

[93] Castle NG, Sonon KE. Internet resources and searching for a residential care setting: What information is available for consumers? J Appl Gerontol 2006; 25: 214-33.

[94] Jefford M, Tattersall MHN. Informing and involving cancer patients in their own care. Lancet 2002; 3: 629-37.

[95] Raupach JCA, Hiller JE. Information and support for women following the primary treatment of breast cancer. Health Expect 2002; 5: 289-301.

[96] Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centers. Br J Cancer 2001; 84: 48-51.

[97] Rogers S, Chen Q. Internet community group participation: Psychosocial benefits for women with breast cancer. J Comput Mediated Commun 2005; 10: article 5.

[98] Joinson, AN. Virtual methods. Issues in social research on the Internet. In: Hine C, Ed. New York: Berg 2005; pp. 21-34.

[99] May C, Gask L, Atkinson T, Ellis N, Mair F, Esmail A. Resisting and promoting new technologies in clinical practice: the case of telepsychiatry. Soc Sci Med 2001; 52: 1889-901.

[100] Mills EM, Davidson R. Cancer patients' sources of information: use and quality issues. Psychooncology 2002; 11: 371-8.

[101] Schulz JH, Binstock RH. Aging nation. The economics and politics of growing older in America. Baltimore: The John Hopkins University Press 2008.

[102] National Library of Medicine. Strategic Plan for Addressing Health Disparities 2004- 2008, 2004. Available from: http://www.nlm.nih.gov/pubs/plan/nlm_health_disp_2004_2008.html

[103] Boulos KMN, Maramba I, Wheeler S. Wikis, blogs and podcasts: A new generation of web-based tools for virtual collaborative clinical practice and education. BMC Med Educ 2006; 6: 41-9.

[104] Lopez-Perez FR, Roncero GPP. Assessing the content and quality of information on the treatment of postmenopausal osteoporosis on the World Wide Web. Gynecol Endocrinol 2006; 22: 669-75.

[105] Morahan-Martin JM, Anderson CD. Information and misinformation online: Recommendations for facilitating accurate mental health information retrieval and evaluation. Cyberpsychol Behav 2000; 3: 731-46.