Review

Use of the internet by breast cancer patients

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Accepted 3 August, 2011

This article reports on the literature associated with Internet use by breast cancer patients. Reviewing the literature indicates that breast cancer patients can use the Internet as a source of information, social support, shared experience, empowerment, positive role models, professional support and patient advocacy. Also, studies reveal that a number of factors such as patients’ personal characteristics, computer competence, computer access, attitudes of patients toward Internet and trust influence patients’ decisions to use Internet to get cancer related information. It is suggested that health care providers should help patients to understand the role of Internet in their health care. Furthermore, they should encourage them to learn and use a credentialed website that is comprehensive and regularly updated by objective and unbiased experts to assist them in coping with their disease.

Key words: Internet use, breast cancer, psychological factors, social factors, knowledge, skill, access, attitude toward internet, culture, trust.

INTRODUCTION

Researchers have reported that one of the most common cancers among women and the second most important cause of women’s deaths is breast cancer (Ryhänen et al., 2010). Worldwide over million women are diagnosed with breast cancer annually. According to Parkin et al. (2005), the breast cancer incidence is highest in North Europe and North America, intermediate in Mediterranean countries and South America and lowest in Asia and Africa. In fact, breast cancer is a chronic illness and people with breast cancer often suffer from anxiety and depression. Not only this disease affects patients’ quality of life but also the physical and emotional aspects of the disease can influence family members, particularly when they become involved in care-giving responsibilities (Ryhänen et al., 2010). According to Brashers et al. (2002), education is important for both the person who is ill and also for his or her family. Education can increase patients’ knowledge about their health problems and cure. Hence, they can be empowered to participate in decisions on their care (Ryhänen et al., 2010). Some researchers such as Craigie et al. (2002) believed that the Internet is an important information resource and can improve patients’ knowledge regarding their health problems. Breast cancer is one of the most common health related search topics in the Internet (Meric et al., 2002). Breast cancer patients can use the Internet as a source of information, social support and communication. Fogel et al. (2002) stated that Internet has a potential to help patients to seek information about their specific type of cancer and to validate the recommended treatment. Gathering information for patients could increase their confidence in interacting with physicians, improve their understanding of health information, and reduce patients’ stress, depression and loneliness. In fact, these information are an essential form of support throughout the illness, from receiving a cancer diagnosis to the end of treatment and also for a significant time afterwards (Fogel et al., 2002). It is a fact that breast cancer patients need information and support.
Health care professionals, family members and social network can provide information and support for patients to cope effectively with their personal and environmental problems (Fogel et al., 2002; Sofka, 1997). Although these sources are valuable for patients, they will not be ready just any time they need them. Hence, an online program is a choice that can provide an informative and supportive environment when geographical and synchronous barriers make others impossible to access (Fogel et al., 2002).

According to Mandl et al. (2000), the number of patients using Internet to search information about their illness and care have increased. Despite the increased online activity by patients, there are limited research studies regarding Internet use by patients and their families. The current study is based on this pressing need and will discuss about: 1) the role of Internet on breast cancer patients; 2) the potential psychological benefits of Internet use; and 3) the factors related to use of Internet by breast cancer patients for information related health issues. This study will contribute significantly to the existing knowledge in the use of Internet by breast cancer patients. Also, it can be useful for health care providers, professionals and related area scholars to understand better how Web-based intervention programs can help breast cancer patients.

ROLE OF INTERNET ON BREAST CANCER PATIENTS

The world's largest online medical library is the internet (Harrison et al., 2007). Approximately, more than 1.5 billion Internet users worldwide (Steele et al., 2009) can access to over 100,000 health-related websites (Harrison et al., 2007). According to Balka et al. (2010) Internet based delivery of health information is often viewed as an optimal way to disseminate health information because it offers privacy, immediacy, a wide variety of information and a variety of perspectives” (Balka et al., 2010). One of the top three disease that patients and their family frequently seek information on the Internet is cancer (Dolinsky et al., 2006). “As a group, breast cancer patients have been quick to adopt the Internet as a source of health information” (Dolinsky et al., 2006). In a quantitative study about Internet usage among women with breast cancer, Pereira et al. (2000) found that 43% of the patients used the Internet to look for cancer-related information. Similarly, Chen and Siu (2001) reported that information seeking was common among cancer patients in Canada and these patients believed that media and the Internet are powerful means of medical information dissemination. Regarding the advantages of Internet use for health and medical information, Ziebland et al. (2004) stated that breast cancer patients can access to a wide range of information and support needs. In other words, Internet has tangible and intangible effects on users' knowledge about health care matters (Baker and Wagner, 2003). In fact, access to a wide array of information makes patients more comfortable or confident about their care (Baker and Wagner, 2003). Furthermore, “information gleaned from the Internet may improve patients' ability to interact efficiently and productively with health care professionals. In some cases, it may make them better able to care for themselves and reduce the need to consume expensive health care resources with problems that can be managed without additional help” (Baker and Wagner, 2003). Therefore, the Internet can be considered as a useful tool to provide valuable information to everyone who seeks information online (Baker and Wagner, 2003). In line with this idea, Heller et al. (2008) stated that Internet or interactive computer-based patient education programs can increase patients' knowledge level about breast cancer. Knowledge influences the patients’ optimism about their options for treatment (Street et al., 1995). Moreover, it was reported that Internet is a more effective method than written educational materials to increase knowledge (Street et al., 1995). Ozanne et al. (2007) carried out a study about computerized decision aid for breast cancer prevention. Their findings showed that the level of patients' information competence that spent more time in using Internet was higher than patients who spent less time using this kind of services. In fact, Internet offers a number of attributes that can positively impact patients' autonomy, competence, and relatedness (Gustafson et al., 2008).

According to Foster and Roffe (2009), Internet can help breast cancer patients “to increase awareness about particular conditions; to understand diagnoses; to access information about treatments, including complementary therapies; to learn about living with cancer; to tackle isolation by making social connections and gaining support from others; and to access other people's experiences”. Also, the Internet especially can increase relationships (Rice, 2006). Online communities can provide better and different kinds of social capital (Rice, 2006). For example, “participation in online discussion forums can help people to stay in touch with friends and family, share their experiences and form new social networks by providing access to people online who they would not otherwise come into contact with” (Foster and Roffe, 2009). It would seem that Internet is an important source in providing information for breast cancer patients and survivors regarding medical and psychological issues relevant to their illness and treatment (Fogel et al., 2008). Using Internet not only can create a change in patients' thoughts about their health but also it can make subsequent health-related behavioral changes (Iverson et al., 2008). Therefore, online information gathering can
foster more patient engagement in health maintenance and care (Iverson et al., 2008).

**Psychological effects of Internet use by breast cancer patients**

The importance of social support for health is supported by a large body of literature (Fogel et al., 2002). According to Sofka (1997), social support is a multidimensional concept and comprised of informational, emotional, and instrumental support. Informational support involves sharing advice, suggestions, directives, and factual information. Emotional support involves behaviors or actions that offer caring, love, empathy, and trust. Instrumental support involves the provision of tangible resources such as financial assistance. These aspects of support help patients to cope effectively with personal and environmental problems (Sofka, 1997). Madara and White (1997) emphasized that Internet groups offer social support, shared experience, information, empowerment, positive role models, professional support and patient advocacy. This is supported by Bacon et al. (2000) who studied on a support group for widows on the Internet and showed that Internet use helped them reduce their isolation and cope with their loss (Bacon et al., 2000). Similarly, Shaw et al. (2000) stated that “use of online support groups can increase access to a large number of individuals with similar problems, the ability to circumvent the temporal and geographical constraints of face-to-face support groups, and greater anonymity among participants resulting from the reduction of nonverbal cues". Moreover, Im et al. (2007) found that patients who used online support group were much more satisfied than traditional face-to-face support groups because they did not need transportation and they could get more up-to-date information through online support group. It would seem that Internet use for medical information can increase social support by reducing social isolation, increasing personal empowerment and self-esteem (Fogel et al., 2002). In addition, Fogel et al. (2002) carried a study on 251 breast cancer patients to investigate the potential psychological benefits of Internet use. They found that use of the Internet for information on breast health issues was associated with greater social support and less loneliness in women with breast cancer. They did not find any association of Internet use with depression, stress, and coping.

Regarding Fogel et al. (2002) findings, Rogers (2003) stated that innovations are more likely to be used by socially connected individuals. This implies that those who are more likely to use the innovative Internet technology are those who originally had greater social support and less loneliness and that Internet use is not offering them greater social support or less loneliness.

**Factors related to Internet use by breast cancer patients**

Demographic characteristics have caught the attention of many researchers and have been the subject of numerous studies in relation to Internet use for medical information (Fogel et al., 2002; Mandl et al., 2000; Pereira et al., 2000). According to Rogers (2003), individuals' characteristics and the nature of the social system influence on adoption of an innovation. A research done by Pereira et al. (2000) to identify the level of Internet use among women with breast cancer depicted that women who had used the Internet to find cancer-related information were significantly younger, better educated, less satisfied with the amount of treatment-related information given by caregivers, and more interested in getting more information on their cancer and its treatment than those patients who had not used the Internet to find cancer related information. Moreover, Fogel et al. (2002) conducted a quantitative study to examine the potential psychological benefits of Internet use and how it varied as a function of race/ethnicity among 180 white, African American and Hispanic American breast cancer patients who used the Internet for medical information. They found that age, length of time since diagnosis, and breast cancer stage were not significant predictors of Internet use while increased income and educational level were significant predictors of Internet use. This is supported by Pautler et al. (2001) who studied about Internet use by patients with prostate cancer and found that income is strongly associated with Internet use and is a significant predictor of use of the Internet by patients with serious illnesses. Similarly, Mandle et al. (2000) found that Internet use and access are correlated with income (r = 0.43) and maternal education level (r = 0.42) and paternal education level (r = 0.42). Furthermore, Diaz et al. (2002) conducted a study on patients' use of the Internet for medical information and found that patients who had used Internet (53.5% ) for getting medical information were more educated (P < 0.001) and had higher incomes (P < 0.001). In line with this idea, Simms (2006) stated that several factors such as age, income, education, family situation, computer ownership, and Internet access at home, as well as geographic location can explain lower level of computer and Internet use by African Americans.

In addition, Fogel et al. (2008) suggested that “the digital divide/digital inequality, culture-specific online support and trust concerns” are factors that influence the utilization of Internet by cancer patients (P: 705). According to Fogel et al. (2008), “the digital divide refers to differences in internet access or use”. Access to
computer and Internet has often been the most important barriers for using online information by patients. In fact, "this new technology is transforming the way information is being created and distributed among patients" (p: 134). Therefore, patients should have access to high-speed Internet to get information regarding their problems. Also, "they should learn to use this new technology to have any chance of being successful in the emerging knowledge economy" (Wilson et al., 2003). In fact, "rates of access exceed rates of use" (Mandle et al., 2000: 511). In a review of literature regarding Internet use by breast cancer patients, Mandle et al. (2000) stated that access is directly related to income and education. In other word, "income is a major determinant of whether an individual can afford to buy a home computer or pay for home Internet access" (Wilson et al., 2003: 136). Besides, education can help patients to learn the new skills and procedures required to search the Internet for health information. Wilson et al. (2003) reported that "Americans with a college education are almost 6 times as likely to have a home computer (75.7% compared with 12.8%) or home Internet access (69.9% versus 11.7%) as those with an elementary school education" (p: 136). Also, he added that "income and education together account for half of the racial differences in Internet access" (p: 136). "Computer and Internet users are divided along the lines of race" (Wilson et al., 2003: 134). Wilson et al. (2003) reported that the number of White households who had a computer at home (40.8%) were more than Black (19.3%) or Hispanic (19.4%) households and this relationship held across all income levels. Similarly, Mandle et al. (2000) pointed out that White patients were more likely to use or have access to the Internet and e-mail than black and Asian patients. However, in logistic regression models, which included race, Hispanic ethnicity, and income, only income was a significant predictor of Internet use. In a cross-sectional study on 3023 sample of patients in the Paris, Renahy et al. (2008) found that "access to the Internet varies according to social and socioeconomic status and health status, and its use for health information seeking varies also with health beliefs, but not to health insurance coverage or health-care utilization" (p: 5). It is clear that economic and social inequalities have a significant impact on Internet access and on the use of the Internet by breast cancer patients for health information seeking.

In addition, "geographic location plays a major part in determining who owns a computer and who has home access to the Internet" (Simms, 2006). "Urban residents are far more likely to have access to computer services than their rural counterparts (for example, DSL, cable modems and digital television)" (Simms, 2006). Although patients who live in rural areas may be understood the importance of the Internet use on their health care, because they do not have access to internet, they cannot use it to get information. Thus, social factors, particularly income, education, age; limit access of certain groups to these services may cause disparities in health outcomes as Web-based services become integral to health care provision (Simms, 2006). On the other hand, Benigeri and Pluye (2003) stated that: "universal access to the Internet will not eliminate disparities in the use of available health and medical information". Access is an essential condition, but it is not sufficient. In fact, "the most important barriers to the use of health and medical information on the Internet are the difficulties in finding it and, for a large part of the population, in understanding and using it properly" (Benigeri and Pluye, 2003). Renahy et al. (2008) reported that social isolation, Internet experience, frequency of Internet use, and the number of years of Internet use have a significant relationship with Internet use. Also, they added that people who are concerned about their health problem, those who are worried about their health or those who had difficulty understanding advice from physicians were more likely to seek health information online than the others. In fact, Internet plays an important role in patients' live that have a habit in searching information on the Internet and it can be a "useful complement for secondary prevention, especially for better understanding health problems or enhancing therapeutic compliance" (Renahy et al., 2008). "Electronic health tools provide little value if users have lack of knowledge and skills to effectively use them" (Norman and Skinner, 2006). "The concept of e-Health literacy is introduced and defined 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 and Skinner, 2006). In a systematic review of computer use by patients, Dominic et al. (2009) stated that individuals must have the necessary general prose literacy, computer literacy and health literacy skills to function effectively in today's society. These skills help them to "navigate their way through websites often containing complicated and questionable information with regards to credibility and accuracy of content".

Hargittai (2002) carried out a study on random sample of Internet users from a suburban county in the United States. He suggested that there is a significant difference between ability of individuals to find various types of content on the Web (skill) and how long it takes to complete online tasks. Internet skill levels play a major role in finding health information on the Internet. Norman and Skinner (2006) introduced a model of e-health literacy. In their model, they suggested that patients should have a multiple literacy skills such as traditional literacy and numeracy, computer literacy, media literacy, science literacy, information literacy, health literacy. These skills help patients to use Internet effectively. Also,
they stated that health educators should recognize these skill sets and how they relate to the use of new information technologies as a tool for healthcare and health promotion with individuals of diverse literacy skills and abilities. In addition, Fogel et al. (2008) stated that, trust is a significant predictor in explaining the level of Internet by breast cancer patients for breast health issues. Face to face health care providers not only should gain trust of patients, providers of online support groups but also should similarly do. In order to build the trust of patients to participate in online cancer support groups, healthcare providers must take into account patients’ cultural beliefs, attitudes and healthcare practices about cancer (Fogel et al., 2008). According to Rogers (2003), people’s attitudes toward a new technology are a key element in its diffusion. Dolinsky et al. (2006) conducted a study about breast cancer patients’ attitudes toward clinical trials that was offered through the radiation oncology clinic at the University of Pennsylvania and on the OncoLink website. They found that attitudes toward Internet use play an important role in determining to what extent Internet are used. Also, they reported that breast cancer patients using the Web were more likely to be interested in clinical trials testing new drugs or therapies [71 (53%) versus 4 (17%), \( p = 0.002 \)]. Ertmer (2005) discusses the importance of attempting to overcome problems caused by individuals’ attitudes concerning ICT, referred to as second-order barriers, before first-order barriers are tackled.

First-order barriers such as the lack of access or training are more readily observed and more easily tackled, whereas second-order barriers may require major changes in daily routines and underlying beliefs about effective practice. Therefore, enhancing individuals’ attitudes toward computer is one of the greatest challenges to successfully utilize the technology (Baylor and Ritchie, 2002).

CONCLUSION

The present study adds to a growing body of research that describes the advantages of the Internet use by breast cancer patients, factors that is related to Internet use, and psychological benefits of Internet use by breast cancer patients for breast health issues. Also, findings of this reviewing literature support the theory that health-related information on the Internet may play an important role in patient ability to function as confident partners in their own health management. According to Perira et al. (2000), patients of the 21st century are not like patients of the past. Many of them like to get more and new information about their illness. In fact, internet as a means of sharing information can help patients to get cancer-related information in order to cope with their illness. Reviewing the literature indicated that breast cancer patients use Internet to get medical information through three main ways: i) searching for health information; ii) participating in support groups; and iii) interacting with health professionals. Many website on the Internet provide valuable health information for patients. Patients, who are younger, better educated, less satisfied with the amount of treatment-related information given by caregivers, more interested in getting more information on their cancer and its treatment, and have higher income and competence; use Internet more. Furthermore, online health support groups provide support and information for patients. Some researchers reported that these online support groups are “more helpful than physicians in numerous ways (for example convenience, emotional support, cost-effectiveness and in-depth information)” (Cline and Haynes, 2001). Furthermore, physicians can support patients by e-mail and create virtual support groups where patients can interact. Therefore, it is necessary that health care providers help patients to access computers in homes and public places. Also, they should help patients learn to use the Internet and organize information. They should encourage breast cancer patients to use a credentialed Web site that is comprehensive and regularly updated by objective and unbiased experts to assist them in coping with their disease (Fogel et al., 2002). It is anticipated that this study will open new lines of inquiry regarding the Internet use by patients.

Empirical researches should be conducted to answer the many questions posed by this exciting technology. For example, future research can investigate the quality of the websites used by different groups of patients, the types of information sought by different groups and the involvement of Internet use for patient decision-making among different groups of patients.

REFERENCES


