

INTERNET USE AND BREAST CANCER SURVIVORS

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ABSTRACT

A survey was administered to 400 breast cancer survivors at hospitals and support group meetings in Peninsular Malaysia to explore their level of Internet use and factors related to the Internet use by breast cancer survivors. Findings of this study indicated that about 22.5% of breast cancer survivors used Internet to get information about breast health issues. They had access to computer in their more personalized spaces such as at their home and in their workplace. Breast cancer survivors tended to use Internet to get information about cancer and treatment options especially on radiotherapy, chemotherapy, health management, treatment side effects and dietary practice. Majority of Internet users believed that information on the Internet were not useful to improve their knowledge about health care issues. Also, significant relationships exist between level of Internet use and five independent variables, including, age, education level, annual income, residence, and race/ethnicity. It is suggested that health care providers should realize how Web-based intervention programs can help breast cancer patients and then encourage patients to use Internet to get highly information to integrate them into their medical and psychological care.

Keywords: Internet use, education, breast cancer survivors, information, demographic characteristics

INTRODUCTION

One of the most common cancers among women and the second most important cause of women's deaths is breast cancer (Gopal, Beaver, Barnett, & Ismail, 2005). According to the Malaysian National Cancer Registry (NCR) 2006 report, there were about 3525 female breast cancer cases in this country (Zainal Ariffin Omar., Zainudin Mohd Ali., Nor Saleha Ibrahim., & Tamin., 2006). "A Malaysian women's cumulative risk of getting breast cancer during her lifetime is 1 in 19 with the highest risk being in Chinese women (1 in 14)" (Parsa, Kandiah, Mohd Zulkefli, & Rahman, 2008, p. 221). Approximately, out of 100 women who are afflicted with cancer, 30 of them will be breast cancer patients (Lim, Yahaya, & Lim, 2003). This data shows that breast cancer is a serious disease in Malaysian society.

According to Brashers, Goldsmith and Hsieh (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 (Gopal, et al., 2005). Some researchers such as Craigie, Loader, Burrows and Muncer (2002) believed that the Internet is an important information resource and can improve patients' knowledge regarding their health problems. In line with this idea, 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 can increase their confidence in interacting with physicians, improve their understanding of health information, and reduce patients' stress, depression and loneliness (Othman, Blunden, Mohamad, Mohd Hussin, & Jamil Osman, 2010). Although online education is popular alternative compare with traditional method and provides an informative and supportive environment; limited research has been conducted in Malaysia on this issue. The current study is based on this pressing need and addresses the following questions:

- 1) What is the level of Internet use by breast cancer survivors for information related to breast health issues?
- 2) What is the relationship between the level of Internet use by breast cancer survivors for information related to breast health issues and selected independent variables (age, length of time since diagnosis of breast cancer, stage of breast cancer, educational level, income, race, and residence)?

Role of Internet on Breast Cancer Patients

The world's largest on line medical library is the internet (Harrison, Barlow, & Williams, 2007). Approximately, more than 1.5 billion Internet users worldwide (Steele, Mummery, & Dwyer, 2009) can access to over 100,000 health-related websites (Harrison, et al., 2007). According to Balka, Krueger, Holmes, and Stephen (Balka, Krueger, Holmes, & Stephen., 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"(p. 389). One of the top three diseases that patients and their family frequently seek information on the Internet is cancer (Dolinsky, Wei, Hampshire, & Metz, 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, Koski, Hanson, Bruera and Mackey (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 (L. Baker, Wagner, Singer, & Bundorf, 2003). In fact, access to a wide array of information makes patients more comfortable or confident about their care (L. Baker, et al., 2003). Furthermore, "information gleaned from the Internet may improve patients' ability to interact efficiently and productively with health care professionals". According to Ziebland et al. (2004, cited in Foster & 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 & Roffe, 2009, p. 15). 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 (J. Fogel, Ribisl, Morgan, Humphreys, & Lyons, 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, Howard, & Penney, 2008). Therefore, online information gathering can foster more patient engagement in health maintenance and care (Iverson, et al., 2008).

Factors Related to Internet use by Women with Breast Cancer

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 (J. Fogel, et al., 2008; 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, and less satisfied with the amount of treatment-related information given by caregivers than those patients who had not used the Internet to find cancer related information.

In addition, Mandle et al. (2000) carried out a survey to determine sociodemographic predictors of Internet use among 214 patients. They found that Internet use correlated with income ($r= 0.43$) and maternal education level ($r= 0.42$), and paternal education level ($r=0.42$). Also, they added that White patients were more likely to use or have access to the Internet and e-mail than were black or Asian patients, whereas those of Hispanic ethnicity were much less likely. However, in logistic regression models, which included race, Hispanic ethnicity, and income, only income was a significant predictor of Internet use.

METHODOLOGY

This descriptive research investigated the perception of 400 breast cancer survivors at different hospitals and cancer support groups in Peninsular Malaysia. A breast cancer survivor is defined as one that is diagnosed with the cancer. The research employed both quantitative and qualitative methods to obtain the required data. The quantitative method was in the form of a survey. The qualitative approach utilized a focus group interview. This paper is a part of a larger project and focuses on the quantitative part of the study. The instrument was developed from various sources: a review of literature, findings from focus group interview, and pilot testing. The development of the semi-structured focus group questions was initially guided by the "Health Belief Model" (HBM) (Breastcancer.org., 2009). The refinement of the focus group interview guide was also based on feedback from four breast cancer survivors before the actual focus group interviews were carried out. In the focus group

interviews, the interview guide was used to ensure consistency in responses among groups while allowing flexibility for the informants to share their perceptions and experiences during the discussion. A total of five focus groups were conducted with 36 breast cancer survivors from cancer support groups in four states representing the East, Central, North, and South Peninsular Malaysia: Kelantan, Selangor, Penang and Johore. Each focus group was facilitated by two trained moderators and ran for approximately two hours. All focus group discussions were audio-taped and transcribed verbatim by a research assistant. For completeness and accuracy of the transcripts, another research assistant listened to the tapes and reviewed the transcripts. Finally, the focus group moderators reviewed the edited transcripts. For each focus group, the responses to each question were grouped together and read for emerging themes (Merriam, 2009).

The findings from the focus group interview were used for the development of the questionnaire. A panel of expert further examined the content validity of the questionnaire. The instrument was revised according to their suggestion. The reliability of the instrument was administered to 30 patients and the Cronbach alpha coefficient of this questionnaire was 0.81. The finalized survey form was submitted and approved by the research university ethical committee. In this study convenience sampling was used. Researchers assessed respondents who were breast cancer survivors at two locations, (1) hospitals where they do or follow up their treatment, and, (2) support group where survivors attend meetings or participates in the support group activities. At the beginning of data collection session, trained enumerators met with the breast cancer survivors. The purpose of the study and its potential usefulness was explained to the participants. Those who wish to participate were reminded to answer the questions honestly. They were assured of their responses confidentiality. Further, the enumerators briefed them on how to fill the questionnaire. They signed consent to participate form before filling the questionnaire themselves. The enumerators checked the questionnaire for completeness immediately upon return. A total of 400 survivors participated in the study. All the completed survey forms were used in the analysis. In this study descriptive statistics (frequencies, means and percentage) were used to describe and summarize the properties of the mass of data collected from the respondents (Gay & Airasian, 2000). By convention, an α level of 0.05 was established a priori for determining statistical significance.

FINDINGS AND DISCUSSION

The sociodemographic analysis showed that the highest number of the breast cancer survivors were from the Chinese ethnic group (46.50%; n=186) followed by the Malay (44.75%; n=179), and the Indians (7.75%; n=31). In term of religion, less than half of the respondents (45.3%) were Moslem, followed by Buddhist (35%), Christian (12.75%), and Hindu (6%). The women's mean age when they were diagnosed with cancer was 46.9 years. Yip et al. (Yip, Taib, & Mohamed, 2006) carried out a study about incidence of breast cancer from 1993 to 2004 at the University Malay Center and found that the commonest age at presentation was between 40 to 49 years. Moreover, they reported that the mean age at presentation in Malaysia and other developing countries is lower than that in developed countries, where the mean age is 60 years. Furthermore, findings of this study showed that almost half of respondents had 3 to 4 children (41.3%) and majority of them (72.3%) had been survivors for less than five years. Most respondents came from urban area (64.75%) and the vicinities (25.25%). The women were moderately educated. Majority were unemployed (55.25%), fulltime housewives and had relatively minimal income (<RM5000/ year). Most of the survivors (59.5%) had first degree relative with cancer. Among the first degree relatives, in term of ranking, the highest was sibling (29.1%), followed by mother (18.44%) and father (11.73%). These results are consistent with Lynch and Eeles's (2006) arguments that a positive family history is a risk factor for breast cancer. According to Yip et al. (2006), "women who had their first full-term pregnancy after age 30 and women who never had a full-term pregnancy are at higher risk for breast cancer than those who gave birth earlier in life". However, the findings showed that very few women gave birth for the first time when they were above 30 years old. Most of the women (43.75%) breast fed for relatively shorter period (≤ 6 months).

Internet Use by Breast Cancer Survivors

The survey asked 5 main questions from 400 breast cancer survivors regarding use of Internet (frequency of Internet use, usefulness of information, Internet access, information content, and reasons for choosing Internet). A total of 90 (22.5%) of breast cancer survivors taking part in the survey stated that they used Internet often to get information about breast health issues. This finding is not consistent with Chen and Siu (2001) and Koski et al's (2006) studies which conducted in USA and Canada. In fact, level of Internet use in developing countries like Malaysia is lower than that in developing countries. This difference may be because of people's attitudes toward Internet, peoples' perceptions of cultural relevance of Internet in their society, lack of computer access, lack of computer competence, limited local resources, and language (Afshari et al., 2010; Afshari, et al., 2008). Also, findings of this study indicated that high percentage of breast cancer survivors who had used the internet to get cancer-related information were between 45 and 59 years old (57.8%), had secondary education (42.2%),

came from urban area (73.3%), had annual income between RM 20001 and 30000 (22.2%), were in stage 2 of breast cancer (40%), and had been survivors for less than five years (80%).

The study results demonstrated that breast cancer survivors had access to computer in their more personalized spaces such as at their home (12.5%) and in their workplace (7%). In fact, patients' access to computer may change. Computer prices are decreasing, so computer access will increase. According to Mandle et al. (2000), "rates of access exceed rates of use" (p.511). Therefore, "if effective health care interventions are being provided via the Internet, provision of equipment or Internet service to the shrinking minority of patients without access may be cost-efficient and feasible" (Mandl, et al., 2000, p. 510).

Findings of this study indicated that breast cancer survivors used Internet to get information about cancer and treatment options especially on radiotherapy (22.5%), chemotherapy (22.5%), health management (12.8%), treatment side effects and dietary practice (respectively 12.0%). In response to this question "why do you choose Internet as a source of information?" about 15.2% of respondents indicated that they used internet to know more about their problem, 14.5% used it to get general information, 8.8% used it to find other solution to solve problem, and 6.8% used it to reduce anxiety. Furthermore, findings showed that most of the Internet users (81.2%) believed that information on the Internet were not useful to improve their knowledge about health care issues. In fact, this belief is a negative motivator for patients in using Internet. Also, it shows that breast cancer survivors did not understand the ability of the Internet in providing valuable information for breast cancer patients and "improving health care delivery and outcomes" (L. Baker, et al., 2003). According to Heller, Parker, Youssef and Miller (2008), 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 Jr, Voigt, Geyer Jr, Manning, & Swanson, 1995). Moreover, it was reported that Internet is a more effective method than written educational materials to increase knowledge (Street Jr, et al., 1995). Ozanne and his colleague (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). Hence, health care providers 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).

The Relationship between Internet Use and Independent Variables

The association between internet use and independent variables were explored by using the correlation analysis. The correlation matrix shows a number of significant relationships between Internet use and the independent variables (Table 1).

Table 1. Summary of the correlation matrix

Variable	Chi-square	biserial correlation	Sig.
Age		-0.12**	0.041
length of time since diagnosis of breast cancer		- 0.09	0.068
Stage of cancer	5.80		0.21
Education level	46.78**		0.000
Annual income	58.66**		0.000
residence	6.652**		0.036
Race	8.23**		0.043

As can be seen from Table 1, the level of Internet use by breast cancer survivors decreased with age. "This may well change in the future as computer-literate patients become older and computer availability and literacy increases" (Pereira, et al., 2000). Also, in this study, stage of breast cancer and length of time since diagnosis were not significant predictors of Internet use. This is supported by Fogel et al. (J Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002). They 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 Internet use among African American, and Hispanic American was associated with greater social support. Furthermore, they stated 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.

Study results indicated that education level and annual income had a significant relationship with Internet use. It seems reasonable that the higher educational level and higher income; the more familiarity and more access an individual may have with Internet. “These patients may have been exposed to newer technology and have the comfort level to experiment with Internet” (J Fogel, et al., 2002). Hence, it can be concluded that Malaysian breast cancer survivors who have higher educational level and higher income can more likely use the Internet to look up information regarding their illness. This result is consistent with prior studies that higher educational level and higher income are associated with internet use and they are significant predictors of Internet use (J Fogel, et al., 2002; Mandl, et al., 2000; Pereira, et al., 2000). Similarly, residence was significantly related to Internet use. Majority of breast cancer survivor who had come from urban area (73.3%) and the vicinities (23.3%) stated that they applied Internet to get cancer-related information. This may be due to the fact that most data were collected at hospitals and cancer support meetings that had been located in urban area. These places were more accessible to survivors from urban area and vicinity rather than those from the rural.

Furthermore, the findings of this study demonstrated that there was a significant relationship between race/ethnicity and Internet use where Malays used the Internet more than Chinese and Indians. It would seem that Malay women with breast cancer feel more comfortable in using Internet than other ethnic groups (Chinese and Indians). This finding confirmed Fogel et al.’s (2002) study that Internet use is associated with increased social support and race/ethnicity.

Overall, this study supports findings of Mandl et al. (2000) that “patients with limited financial and lower educational level may be excluded from enjoying the benefits of medicine on the Web. Socioeconomic status, race, and health insurance have all been shown to determine social inequities in health outcomes”(Mandl, et al., 2000).

CONCLUSION

This study indicated that about 22.5% of breast cancer survivors used Internet to get information about breast health issues. They had access to computer in their more personalized spaces such as at their home and in their workplace. In fact, access to computer and availability of Internet may motivate patients to go online and get information regarding their illness. Also, “basic education about Internet use will enable patients to exploit the access available to them” (Mandl, et al., 2000). Breast cancer survivors tended to use Internet to get information about cancer and treatment options especially on radiotherapy, chemotherapy, health management, treatment side effects and dietary practice. The study identified four reasons why women with breast cancer sought information on the Internet; 1) to know more about their problem, 2) to get general information, 3) to find other solution to solve problem, and 4) to reduce anxiety. Study results indicated that the majority of Internet users believed that information on the Internet were not useful to improve their knowledge about health care issues. It is clear that the importance of Internet “as a means to disseminate information about health and health care, enhance communication, and facilitate a wide range of interactions between patients and the health care delivery system”(L Baker & Wagner, 2003) has not been understood by breast cancer survivors. 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. Therefore, health care providers should realize how Web-based intervention programs can help breast cancer patients and then encourage patients to use Internet to get highly information to integrate them into their medical and psychological care.

Moreover, findings of this study indicated with increasing age, level of Internet use by breast cancer survivors reduced. Stage of breast cancer and length of time since diagnosis did not display significant relationship with the level of Internet use by breast cancer survivors. Also, significant positive correlations existed between level of Internet use and four independent variables, including, education level, annual income, residence, and race/ethnicity. Therefore, it can be concluded that breast cancer survivors who are using the Internet to get cancer-related information are significantly younger, better educated; have higher income and have come from urban area and vicinity.

This study had several limitations which may influence generalizability of the results. The current inquiry was part of a cross sectional research to identify level of Internet use by breast cancer survivors and relationship between demographic variables and Internet use. Measures of patients’ attitudes toward Internet, their knowledge and skill in using computer, and their cultural perceptions of Internet use were not included. Furthermore, method of sampling was a limitation. Due to limited access to breast cancer survivors, convenience sampling was used in this study. Although “this method is quick and easy to organize, there is no guarantee that the behaviors of these people represent behaviors of other groups.

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