

Evaluation of the Information Needs of Breast Cancer Patients in the Internet

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A B S T R A C T

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Background: Breast cancer is a serious concern for women health. Providing enough information to these patients will increase awareness, level of participation and improve quality of care. To provide information through the internet, identifying information needs is essential. The purpose of this study was to identify information needs that can be available through Internet for women with breast cancer based on their perspectives.

Methods: 120 women with breast cancer, who were familiar with the internet, entered to the study with convenient sampling method from Cancer Institute of Imam Khomeini hospital located in Tehran. The questionnaire was designed in seven areas: disease, treatment, daily activities, sexual health, and impact of disease on the family and private life, disease acceptance and self-image as well as other educational content based on a literature review and six sample portals. Descriptive statistics (frequency, mean and standard deviation) were used to analyze data by SPSS software.

Results: The information content needed by patients on the internet, was in seven areas: Treatment (mean= 4.62 out of 5), daily activity (mean= 4.51 out of 5), disease (mean= 4.42 out of 5), disease acceptance and self-image (mean= 4.37 out of 5), the effect of disease on private life (mean= 4.21 out of 5), sexual health (mean= 4.2 out of 5) and other educational content (mean=4.55 out of 5).

Conclusion: The need for information in the field of treatment is the most important needs of patients. They are interested in accessing through the online medium that provides them with information about cancer, decision making and treatment management. The care team can improve quality of care by providing information through the internet and portals.

Keywords: Information needs, Internet, Breast cancer



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INTRODUCTION:

Breast cancer is the most common cancer among women¹ and it is one of the serious concerns for their health². This disease is the most common cancer around the world among women, with 1.67 million newly diagnosed cases in 2012. It is also considered the most common type of cancer in developed and developing regions³. In the past decade, the incidence of cancer in the Middle East has risen 46 percent and from 495000 in 2005 to 723000 in 2015. In Iran, in 2012, 287372 deaths occurred due to non-contagious diseases, of which 53837 cases were due to cancer⁴. Breast cancer in Iran is ranked first among all types of diagnosed cancers in women, and it is the fifth leading cause of death among Iranian women. According to cancer registry reports, breast cancer has increased in Iran since 1999. Although its death rate is still lower than western countries it has been growing⁵.

Breast cancer has negative consequences for patients and their families⁶. Evidence suggests that patients with breast cancer may not show clear evidence of disease, but they are suffering from its problems including pain, fatigue, fear of recurrence, inability to cope with the disease and its treatment, psychological issues. These problems will remain for a long time after initial treatment⁷. The consequences of this disease, in addition to physical and psychological impact, affect social life of women⁶ and reduce their quality of life⁸.

Looking for information plays an important role in individual's effort to cope with impairing their quality of life, due to diagnosis and treatment of cancer⁹. Access to timely, comprehensive, accessible, and coordinated information is the first empowerment program for breast cancer patients¹⁰. Lack of information and support will put women at risk of augmenting psychological distress and reduce their sense of well-being and satisfaction of care⁶. Providing appropriate information helps women

in managing disease and making informed decisions¹¹. The internet is a new source of cancer-related information¹², which has a beneficial role in the development of continuous care and promotion of health, monitoring chronic diseases, providing information services and implementing home care services¹³. Although there are risks in using the internet due to the lack of information monitoring, patients are increasingly referring to it¹². According to the data from developed countries, more than 50% of breast cancer survivors are using internet as a source of health information¹⁴. The results of the previous studies show that there is a positive relationship between applying internet and computer-based training programs with level of awareness and knowledge of breast cancer patients, which leads to patients' satisfaction¹⁵. According to patients' opinion, using the internet will provide them more information in comparison to the doctors that they refer to them for treatment¹². Internet-based technologies have been recognized as a significant platform to improve care coordination of cancer patients. These technologies can provide valuable opportunities for improving cancer care coordination by increasing relationship between patients and healthcare providers, monitoring side effects, and better patient follow up over distances¹⁶.

For women with breast cancer, achieving self-efficacy mean becoming a beneficial person who is psychologically capable of controlling her self-confidence and is able to decide and manage her treatments¹⁷. Cancer patients retrieve a large amount of information by surfing the internet¹⁸. By receiving appropriate and adequate information, they can express their health preferences and participate in decisions about their disease. Providing information and participation of patients in the decision-making process will improve care quality and treatment of disease and more adherence to treatment. Therefore, greatest attention should be given to concerns of patients with breast cancer and their informa-

tion needs and their preferences¹⁹.

Using internet by patients and their greater participation in healthcare process lead to more confidence in talking to physicians about their concerns and problems, more capability for participation in medical decision-making and better-perceived self-efficacy associated with cancer²⁰. Therefore, Internet as a revolution in recent decades can be effective to provide health information and maintaining change in patients' knowledge and behavior¹³.

Studies have shown that information provided by physicians is not always responsive to patients concerns²¹. A study found that only 19% of the 232 patients were satisfied with the information provided by the physicians²². Women undergoing breast cancer surgery had a high level of information needs, but these needs have remained unmet²³. Understanding information needs of patients with breast cancer enable nurses to help patients manage their treatment and its side effects²⁴. Regarding the information needs, many studies have been conducted to highlight benefits and side effects of radiotherapy, treatment options and the likelihood of cure, spread of disease and treatment options as most essential information needs of patients. But, nowadays, with growing trend of this disease and increase in the level of literacy and expectations of patients, provision of information needs of these patients is not sufficient by using conventional methods, such as use of pamphlet and booklets, and with new methods such as use of the internet and web portals, these information needs can be better answered²⁵⁻²⁷. Tuna found that women's knowledge of breast cancer and breast examinations from 46.52 (before training through the internet) increased to 76.73 (after providing an educational program via internet)¹³. According to studies, Internet-based interventions have a positive effect on empowerment of patients with chronic diseases²⁸.

In order to develop a web application, information needs that can be provided to patients through this medium should be identified. However, a few studies have been done in this regard. In Iran, there is no study on the information needs of women with breast cancer on the internet. In relation to the growing use of the internet and the effective role of this medium in cancer management⁹, and the potential of the internet to help cancer patients and their families to find relevant information²⁹, recognizing information needs to be provided through the internet and its related technologies seems to be necessary. Therefore, the current study aimed to identify information needs of women with breast cancer through the medium of internet.

METHODS:

The present study is a cross-sectional study, conducted from July to October of 2017. The research sample was women with breast cancer who were familiar with the internet. This study was conducted in Cancer Institute of Imam Khomeini hospital, Tehran, because it is a referral center with at least 10,000 patients with a variety of cancer patients with various cultures and religions from the whole country³⁰.

The inclusion criteria for enrolling patients in the study were literacy, familiarity with the internet and computer, and an established diagnosis of breast cancer (new or previous patients). The sample size was 95 patients based on Cochran's formula³¹. The sample size was based on studies in the field of the information needs in Iran³². For completeness of information (for example, incomplete questionnaires), 120 patients were considered. Samples were selected according to the eligibility criteria.

The tool used in this study was a questionnaire designed based on a literature review and comparison of six sample portals. To this end, articles on the content and information needs of breast cancer patients, and

some cancer portals such as the Moffit, the Chico, and the MD Anderson were studied and questions were developed.

The first part of the questionnaire was demographic and diagnostic information of patients (including the level of education, marital status, age, time since diagnosis of disease, type of treatment). The second part contained questions related to the information content needed by patients, consisting of seven areas: disease (9 questions), treatment (8 questions), disease acceptance and self-image (6 questions), and sexual health (3 questions), effects of disease on family and private life (4 questions), daily activity (4 questions) and other educational content (3 questions). Answer options were designed based on the 5 points Likert scale, “completely disagree,” “disagree,” “neutral,” “agree” and “completely agree.” In the questionnaire’s guide, the benefits of internet and portal were generally explained, and patients were asked to describe how much they agree that questioned information provide them by web and portals.

Faculty members evaluated content validity of the questionnaire in the field of health information management, medical informatics and oncologists (experts) and the relevant suggestions were applied, and reliability of the survey was assessed by using Cronbach’s alpha coefficient. To this end, the questionnaire was provided to 30 patients outside of the sample, and the Cronbach’s alpha (0.961) was calculated by using SPSS 24 software.

The questionnaire was distributed among patients after coordination with hospital and oncology ward directors. The researcher was present until the end of completion of the questionnaire in order to answer the possible patients’ questions.

The data were analyzed using the SPSS 24 software.

In order to analyze the data, scores were considered as follows, completely disagree=1, disagree=2, neutral=3, agree=4 and completely agree=5. Then, the frequency and mean of scores were calculated. The relationship between information needs of patients and variables such as education level, age, marital status, duration of disease involvement and type of treatment investigated by using ANOVA and T-test. Research ethics committee of Iran University of Medical Science confirmed the proposal of this study (IR.IUMS.REC 1395.9311304010).

RESULTS:

Based on analyzing 120 questionnaires, the mean age of women participating in the study was 43 years (± 10.86). 30% of patients have diploma, 85% of patients were married and time since diagnosis was more than ten months in 66.7% of patients. Concerning treatment type, 40% of patients performed all types of breast cancer treatment including surgery, radiotherapy, and chemotherapy. Rest of patients experienced only one or two treatments based on the stage of the disease (**Table 1**).

Table 2 represents the patients’ view of their information content needed on the internet, within seven areas, treatment (mean= 4.62), daily activity (mean= 4.51), disease (mean= 4.42), disease acceptance and self-image (mean=4.37), sexual health (mean= 4.2), and effect of disease on private and family life (mean= 4.21) and other educational content (mean=4.55) as information that patients reported tended to be accessible to them in the internet.

The relationship between the patients’ information needs through the medium of internet and variables such as level of education, age, marital status, duration of disease involvement and type of treatment were evaluated by using ANOVA and T-test. There was a

Table 1. Individual Characteristics of women with breast cancer

Variables	Amolicon size	
<i>Age</i>	<30	19 (15.8)
	30-40	48 (40.0)
	41-50	29 (24.2)
	51-60	18 (15.0)
	>60	6 (5.0)
<i>Level of education</i>	Under Diploma	22 (18.3)
	Diploma	36 (30.0)
	Higher Diploma	4 (3.3)
	Bachelor or higher	28 (23.3)
	No answer	30 (25.0)
<i>Married statues</i>	Single	18 (15.0)
	Married	102 (85.0)
<i>Time since diagnosis of cancer</i>	< one month	8 (6.7)
	1- 4 months	21 (17.5)
	5-10 months	8 (6.7)
	>10 months	80 (66.7)
	No answer	3 (2.5)
<i>Treatment type</i>	surgery	31 (25.8)
	Chemotherapy	8 (6.7)
	Radiotherapy	-
	Chemosurgery	27 (22.5)
	Radio surgery	6 (5.0)
	Radio chemotherapy	1 (0.8)
	All	40 (33.3)
	None of them	7 (5.8)

significant relationship between education level and information needs in the field of treatment ($p=0.001$), sexual health ($p=0.004$) and daily activity ($p=0.005$). Individuals with higher degrees needed more information. Also, there was a significant relationship between marital status and information needs in daily activities ($p<0.05$), so that single patients needed more informa-

tion. There was a significant relationship between duration of disease involvement with information needs in private life ($p= 0.020$), and patients with involvement duration of 1-4 months and >10 months needed more information. There was no significant relationship between age and type of treatment with seven areas of information needs.

Table 2. Perspectives of women with breast cancer about information needs

Informational needs	Mean (standard deviation)
Disease	4.42 (0.56)
Treatment	4.62 (0.57)
Disease acceptance and self image	4.37 (0.63)
Sexual healthz	4.2 (0.81)
Personal life	4.21 (0.84)
Daily activity	4.51 (0.49)
Other content	4.55 (0.67)

DISCUSSION:

Providing information is one of the essential elements of targeted care and well-known strategy for patient management. Increasing perceived information by patients increases patients' satisfaction with care and increases their participation in health care decision making and improves treatment, including reducing anxiety and distress. Understanding patients' information needs help to ensure that educational interventions incorporate the required content of patients^{33,34}. The purpose of this study was to investigate information needs of women with breast cancer on the internet, and it was found that these needs are in seven areas of treatment, disease, daily activity, disease acceptance and self-image, the effect of disease on family and private life, sexual health and other educational content. Based on the present study, information content in the field of treatment is the most important priority for women with breast cancer on the internet. In this area, control and management of side effects due to treatment are most prioritized by patients, which mentioned in the previous studies^{24,27,33,35-40}. In the study of Muhammad, breast cancer survivors used internet to obtain information on cancer and treatment options, health management, treatment-related side effects and diet⁴¹. Also, Matsuyama revealed in her study, the in-

formation needs on treatment options were one of the most priorities for patients⁴². In Lee's study, similar results were found: information needs in the field of disease and treatment had the highest priority for patients, initially and during chemotherapy⁴³. In Kimiafar study, need for information on disease management and nutrition during treatments was one of the priorities of patients with breast cancer³².

According to the present study, in terms of disease information, obtaining information on the likelihood of treatment, were among information needs of patients, and patients would be willing to access this information through the internet. Similar results were obtained in the previous studies^{6,9,44,45}. Fallor in his study showed that the most unmet information needs of patients were about the likelihood of cure and treatment²⁶. Additionally, Bei et al. showed that the most patients, regardless of their demographic and clinical features, considered the likelihood of cure one of the main priorities of their information needs so that, this information need was considered as three important priorities⁴⁶.

Regarding disease acceptance and self-imaging, the introduction of counseling and supportive groups has been considered the priorities of information needed by patients through the medium of internet, as noted in previous studies⁴⁷⁻⁴⁹. Cancer patients avoid social

environments due to concerns about other peoples' questions and curiosity⁵⁰. Discomfort caused by diagnosis and treatment of breast cancer impairs their emotional well-being, family life, and their occupation and reduces their quality of life⁵¹. The internet is an important source of information for psychosocial problems associated with breast cancer, and by increasing interpersonal communication and online communities, variety of social services can be provided and patients by participating in online discussion forums, can connect with friends and family members and share their experiences and this experience may be helpful for self-image of patients^{41,52,53}.

Another result of the current study was the information need about diet, which has been highlighted as information priority in the area of daily activity. Malnutrition is the problem of most cancer patients, and active nutrition intervention should be an integral part of cancer treatment⁵⁴. In Iran, 53.1 % of cancer patients, experience some degree of malnutrition in various stages of their treatment⁵⁵, and according to Leandro's study, cancer patients are more likely to be malnourished than others⁵⁶. Genton showed that 70% of breast cancer patients were interested in having nutrition information⁵⁷. Also, Lee noted that dependence on dietary treatments is very important, and when individuals are suffering from disease, nutritional treatments are considered as part of complementary therapy⁴³. Additionally, nutrition and diet can change disease progression, response to treatment and survival rate⁵⁶.

Self-care education was one of the information content needed by patients through the medium of internet. Williams indicated that self-care improve the quality of life of cancer patients by creating a positive impact on management of side effects and participation in care⁵⁸. Aranda showed that with providing some self-care information to cancer patients, some of the side effects of chemotherapy were significantly reduced⁵⁹. Self-care

programs can improve patients' self-confidence and enables them to manage their problems⁶⁰. Roozbahani showed that education through multimedia software increased the intent and performance of mammography⁶¹. Dunbar and Osborn introduce the website and portals as an appropriate tool for providing information and access to educational programs^{18,62}.

According to the current study, effect of the disease on sexual intercourse was another information content needed by patients through the medium of internet. Crowley in his study showed that 50% of patients were worried about changes in their sexual activities⁴⁸. Karaoz indicated that women with breast cancer before menopause need comprehensive information on sexual health⁶³. Impact of the disease on sexual alteration last long after successful treatment and often has physical and emotional side effects⁶⁴. Breasts are a significant part of women's emotion, and they judge their sexual performance according to their physical appearance^{64,65}. Studies have shown that, women with breast cancer have lower levels of sexual satisfaction and have more sexual problems than regular healthy women, while sexual intimacy makes cancer experiences more controllable and help the recovery process, and it is considered as a center for proximity of spouses and quality of life in palliative care⁶⁶⁻⁶⁸.

In the study of Albada, the hospital was evaluated positively because of the existence of a website for genetic counseling for breast cancer and providing information including genetic counseling, breast cancer risk, emotional outcomes, carrier, and inheritance in breast cancer⁶⁹. McNamara indicated that 71% of patients had an interest in online access to health information through the portal and diagnostic information and radiological findings was a priority for 90% of patients⁷⁰. Providing disease-related information and access of patients to the results of tests and consultation services, as well as the existence of website approved by participants in

the study^{71,72}.

Based on the present study, patients with higher education levels needed more information. Other studies emphasized on significant relationship between the level of education and information needs of patients in different areas^{32,46,73}. According to the present study, single patients needed more information on daily activities. In Lyons' study, demographic characteristics were among most important factors in the use of the internet for medical information⁷⁴. In Pereira's study, young women with breast cancer and patients with higher level of education were more likely to use the internet to obtain information⁷⁵. In the current study, patients with 1-4 months and more than ten months of involvement with their disease needed more information on private life. In the Vogel study, patients needed more information at the beginning of treatment⁴⁵. As Halbach showed, the information needs of patients with breast cancer are different throughout treatment⁷⁶. One of the strengths of the study is that this study is the first study in the field of information needs of women with breast cancer on the internet conducted in Iran. However, some limitations should be considered. The study was conducted only in a hospital and included just women with breast cancer with internet familiarity. Therefore, most patients were at an early age, and they were using internet due to their high level of literacy. The study only examined information needs of the female population; therefore, information needs of men with breast cancer were not considered. Thus, the results of the study are not necessarily generalizable to all patients with breast cancer. It is suggested that in future studies, the information needs of men population with breast cancer should be considered.

CONCLUSION:

The current study showed that information content

needed for women with breast cancer through the medium of internet, in terms of treatment and management of treatment side effects is a priority. Considering the significant growth of internet usage, this technology can be used to provide quality and up to date information with the aim of improving knowledge of patients and meeting their information needs. By providing valid information through the internet and its related technologies, patients and their families can access a complete set of information, and the goal of empowering patients through their participation can be realized.

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