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Health information seeking behavior of female breast cancer patients

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Abstract

BACKGROUND AND AIM: One of the methods for involving breast cancer patients in their own treatment is to provide them with credible and simple information. To provide this information, it is first necessary to investigate health information-seeking behaviors of these patients including their information needs, sources, barriers, and attitudes regarding health information.

METHODS: This is an applied type study using survey method. The statistical population included female breast cancer patients referring to Seyed-Al-Shohada Hospital of Isfahan (60 patients). Data gathered through questionnaire.

RESULTS: "Self-care," "emotional-psychological support information," and "treatment length and chance of relapse" were the most sought-after health information by patients. "Brochure and catalog provided by hospital," "other cancer patients," and "physicians and nurses" were the most important information sources. "High cost of information sources," "Lack of response from treatment personal (physicians and nurses)," and "lack or trust in website information" were the most important information-seeking barriers. Regarding attitude, participants stated that health information can help them in areas such as "controlling their conditions," "adapting to their conditions," "stress and anxiety control," and "preforming their social roles" and "hopefulness."

CONCLUSION: Credible and relevant information can help patients to seek their treatment with renewed motivation and energy. This information should be provided for the patients from various sources such as brochures and websites according to their information-seeking abilities and health literacy with low cost. The knowledge of library and medical information experts can be used for evaluation and creation of easy-to-understand information sources.

Keywords:

Breast cancer, health information-seeking behavior, Isfahan, Seyed Al-Shohada Hospital

Introduction

Cause of death worldwide^[1] and the third most common cause of death in Iran.^[2] Breast cancer is the most common cancer in women^[3] and is expected to result in significant loss of human and financial resources in the coming years.^[3] Various factors such as smoking, alcohol consumption, diet, obesity, and lack of physical activity can lead to cancer.^[4] The negative effects of these factors can be reduced using health-care measures which

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require providing the necessary information for patients, especially women. [5] Health conditions of women can directly affect the health situation of families and society as a whole due to their core role in families. [6] Credible and easy-to-understand information can lead to better participation of patients in their own treatment procedure.^[7] Health information is one of the bases of any health-care system and is required to promote self-care and improve health literacy^[8] and is directly affected by health information-seeking behaviors of patients. Health information-seeking behavior is defined as "the sum of activities attempted by an individual after determining their information needs to meet this need."

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Health information-seeking behavior includes several aspects including health information needs, health information sources, health information barriers, and patients' attitude toward health information.^[9]

Among concepts related to health information seeking are:

- The type of health information sought
- The extent of the acquired health information
- Factors related to information sources such as credibility and accuracy
- Factors related to massages in information sources such as clarity or ambiguity
- Personal characteristics of the information seeker including their understanding about their condition^[10]
- Health information behavior studies are divided into several main phases including information needs, information resources, and barriers, with backgrounds for each phase presented, respectively.

Information needs

The study by Tilleul *et al.* showed that, if patients are not informed about their level of activity after a surgery, they might have to visit hospitals to acquire the necessary information, increasing the cost of care, and stress in themselves and their caregivers. ^[11] Keinki *et al.* reported that cancer patients, despite understanding regarding the importance of diet, are uncertain regarding their diet due to conflicting information. ^[12] Tariman *et al.* determined the information need priorities or middle-aged patients suffering from bone marrow cancer. They identified three most important information needs as treatment, diagnosis, and self-care with internet, physicians, family, and friends being the most important information sources. ^[13]

Gholami *et al.*, in their study, investigated information needs of cardiovascular patients. Their findings showed that information regarding prognosis, their roles, physical and mental health, health-care system performance, novel, traditional, and Islamic medical practices were among the information sought by these patients. Therefore, they concluded that it is necessary to provide the information using various sources to meet the information needs of patients and increase their participation in the treatment process.^[14]

Nasrollahzadeh stated that the most important health information needs of women include psychological needs, nutrition, maternal care, and childbirth methods with lack to time, lack of ability for validating information sources, and high level of knowledge available acting as the most important barriers.^[15]

The findings of the study by Riahi *et al.* showed that general health and medical information are the most important information needs.^[16]

Robinson *et al.* reported that analysis of questions asked by patients is a useful and powerful method for determining their information needs. In this case, identification and evaluation of patients' information needs are carried out based on their own reports. With the increased ability of surgeons to meet their patients' information needs, their patient-centric view improves, leading to improve patient satisfaction and improvement in clinical instructions.^[17]

Information resources

Robinson et al. found that analyzing patients' questions was a useful and powerful way to meet patients' information needs. Because researchers identify and edit patients' information needs which are reported by the patients who are directly involved. By enhancing the surgeons' ability to inform patients about their needs, their patient viewpoints improve, which in turn increases both patient satisfaction and improved clinical guidelines.[17] The findings of Riahi et al. research showed that families, friends, relatives, and other immigrants are the most important channels for access to information. [16] Kahouei et al. reviewed the information needs regarding women's health who have been under surgery. The manual and the doctor were their most important source of information.^[7] Valero-Aguilera et al. surveyed the information needs and use of the internet in patients with breast cancer and urinary and reproductive system cancer. Patients were eager to share their experiences with other patients to help them cope with the disease. [18] Tariman et al. reviewed the priority information needs of adults with active bone marrow cancer. The Internet, doctors, family, and friends were the most important sources of health information. [13] Mayer et al. studied the cancer survived information-seeking behavior of patients. The internet was the most important source of information for them.^[19] Feizi et al. reviewed information seeking about the carcinogenic factors and cancer warning signs. The most important sources of information about cancer were, respectively, media, personal studies, and friends.^[20] Zare Gavgani et al. studied the health information of members of public libraries in Qazvin. The most common ways to get health information were watching TV and browsing search engines.[21]

Obstacles

Findings of research by Riahi *et al.* showed that lack of mastery of the use of print and internet information resources is the most important barrier to access to information. [16] Latifi *et al.* examined the barriers to the health information of women with breast cancer after mastectomy. The findings showed that three factors including "fears," "shame," and "inadequate information literacy" were the main individual barriers. [22] Milewski and Chen reviewed the barriers to

obtaining medical information in patients with diabetes. The most important obstacles were lack of motivation, passivity, inconsistency in information, and inability to find useful information.^[23] Nasrollahzadeh studied the health information behavior of pregnant women. The most important barriers to gain information were lack of time, inability to assess material credibility, and high scientific levels of book content.^[15]

Generally, studies have shown that patients require more education regarding treatment and self-care. However, this education is not possible without proper need assessment. Therefore, it is necessary to first determine the health information-seeking behavior of patients (including needs, barriers, sources, and attitudes regarding health information). It is also necessary to attempt and remove all health information barriers for patients to achieve health-care goals.

Seyed-Al-Shohada Hospital of Isfahan is the only public cancer treatment center in Isfahan which services patients from Isfahan as well as surrounding cities and provinces. Studies show that breast cancer is the most prevalent cancer in Isfahan, [24] with an increasing trend of breast cancer prevalence also being observed in Iran.^[25] However, despite the importance of this topic, few studies have been conducted regarding health information-seeking behavior of breast cancer patients in Iran. Since patients' access to relevant, credible, and timely information in a usable format can help prevent waste of time and resources as well as repeated and unnecessary treatments, providing relevant health information is one of the duties of medical informatic experts due to their role as a bridge between information sources and information users. [26,27] To better perform this duty, it is necessary to first identify health information needs of patients and then provide them with the necessary sources of information. To this end, the goal of the current study is to determine health information-seeking behavior of female breast cancer patients in Seyed-Al-Shohada Hospital of Isfahan in year 2017. Specific objectives include determining the health information needs of women with breast cancer in Seyed-Al-Shohada Hospital, determining the barriers to accessing health information from their point of view, and determining the attitudes of these patients. Some of the practical goals are to provide the necessary suggestions to medical information professionals to fit the resources and channels of information based on patients' information needs, provide suggestions for removing the barriers and problems of women with breast cancer in accessing health information, provide suggestions for the development of health information sources, and provide a solution to hospital authorities and policymakers to provide appropriate infrastructure

for easy access of patients to valid information. The results of this study will be given to these individuals.

Methods

This is an applied type study carried out using survey method. The statistical population is female breast cancer patients visiting Seyed-Al-Shohada Hospital of Isfahan in year 2017 (1396). According to the hospital logs, there was a total of 150 breast cancer patients, 60 of which visited the hospital for follow-up checks in summer 2017. The questionnaire was distributed among these sixty patients. The questionnaire of Riahi et al.[16] was used for data gathering after some adjustments to match the current study. The items of this questionnaire included questions on health information, health information sources, health information-seeking barriers, and patients' attitude toward health information. Data were gathered through visiting the hospital. After explaining the study to patients, their consent and their family's consent were acquired for participation in this study. The validity of the questionnaire was determined by librarianship and medical informatics experts, oncology experts, and nursing faculty members (patient education). To determine the reliably of the questionnaire, it was first distributed among 25% of the statistical population (15 patients) and the results were used to calculate the Cronbach's Alpha coefficient which was equal to 0.83. After gathering data, the results were analyzed using descriptive (frequency, percentage, and average) and analytical statistics (independent t-test, ANOVA, and Spearman and Pearson's correlation tests) using SPSS software version 18 (IBM Company, Armonk, NY, USA).

Results

Findings showed that the majority of participants (35%) were in the 40–49 age group with the least number of participants in the 29–35 age group (5%). The majority of participants (61.7%) were married and only 5% were single. The majority of participants lived in surrounding cities (38.33%) with 28.33% living in rural areas. The majority of participants (45%) had elementary school level literacy with very few having PhD level education (1.67%).

The study findings regarding information needs of female breast cancer patients in Seyed-Al-Shohada Hospital of Isfahan showed that information regarding "Self-care," "emotional-psychological support information," and "treatment length and chance of relapse" was the most sought-after health information by patients with average scores of 4.80, 4.53, and 4.33, respectively. Data presented in Table 1 are percentages and scores from 1 to 5 Likert scale [Table 1].

The findings regarding health information-seeking barriers of female breast cancer patients in Seyed-Al-Shohada Hospital of Isfahan showed that "high cost of information sources," "lack of response from treatment personal (physicians and nurses)," and "lack or trust in website information," with respective average scores of 4.63, 4.53, and 4.52 were the most important information-seeking barriers. Data presented in Table 2 are percentages and scores from 1 to 5 Likert scale [Table 2].

Research findings regarding information sources of female breast cancer patients in Seyed-Al-Shohada Hospital of Isfahan showed that "brochure and catalog provided by the hospital," "other cancer patients," and "physicians and nurses" were the most important information sources with respective scores of 4.25, 4.22, and 4.20.

In questions regarding patients' attitude, participants were asked whether access to medical information can help in controlling their conditions and fulfilling their social roles and whether access to medical information can improve hopefulness and adaptability or leads to increased fear and anxiety. The results showed that access to health information can help patients in "controlling their conditions," "adapting to their conditions," "stress and anxiety control" (with joint average score of 4.67), and "performing their social roles" and "hopefulness" (with average scores of 4.33 and 4, respectively).

Discussion

Breast cancer is one of the most prevalent and costly cancers among women.[28] One of the methods to reduce the costs of this condition is to provide cancer patients with valid, credible, and relevant information and encourage them toward self-care. The findings showed that, according to patients, information regarding "Self-care," "emotional-psychological support information," and "treatment length and chance of relapse" were their most important information needs. These results are similar to the results reported by several studies including Tariman et al. regarding information needs of middle-aged bone marrow cancer patients, [13] Valero-Aguilera et al. regarding information needs of orology and breast cancer patients, [18] Mistry et al. regarding health information needs of cancer patients during their treatment, [29] Riahi et al. regarding health information needs of immigrants, [16] Nasrollahzadeh regarding information needs of pregnant women,[15] and Nasiri et al. regarding information needs of patients after heart valve replacement.[30] On the other hand, these results are different from those reported in some studies including the results of Goossens et al. on "cancer patients' and professional caregivers' needs, preferences, and factors associated with receiving and providing fertility-related information,"[31] the study by Kahouei et al. regarding health information needs of women undergoing obstetrics surgery, [7] and the study by Zare Gavgani et al. on Information-Seeking Behavior

Table 1: Frequency and average score of information needs in female breast cancer patients

Health information needs	Very low	Low	Average	High	Very high	Mean	Rank
The nature, cause, and stages of the disease	13.3	20.0	13.3	33.3	20.0	3.27	10
Risk factors and chance of recovery	26.7	6.7	0	26.7	40.0	3.47	8
Duration of treatment and the risk of disease return	0	1.7	6.7	48.3	43.3	4.33	3
Medical information	6.7	0	6.7	40.0	46.7	4.20	4
Find the right doctor and treatment center	11.7	18.3	1.7	35.0	33.3	3.60	7
Find insurance with maximum cover for treatment costs	8.3	11.7	3.3	28.3	48.3	3.97	5
Types of therapeutic methods (Traditional and Islamic Traditional Medicine)	25.0	5.0	33.3	31.7	3.4	3.42	9
Laboratory tests and radiology photographs	8	30	33.3	26.7	3.6	3.68	6
Self-care (diet, sexual function, physical activity, etc.)	0	0	20.0	80.0	4.8	4.80	1
Emotional and psychological support (counseling)	0	0	46.7	56.3	4.5	4.53	2

Table 2: Frequency and average score of health information-seeking barriers in female breast cancer patients

Obstacles to access to health information	Very low	Low	Average	High	Very high	Mean	Rank
Lack of access to information resources, libraries, and the internet	53.3	31.7	1.70	6.7	6.7	1.82	10
High costs of access to information resources	0	1.7	0	33.3	65	4.62	1
Physical and physical conditions inappropriate	3.3	1.7	1.7	86.7	6.7	3.92	5
Failure to master information search	0	1.7	0	66.7	31.7	4.28	4
Lack of familiarity with medical terms and English language	10.0	56.7	3.3	60.0	0	3.13	7
Not having enough time	23.3	35.0	15.0	10.0	16.7	2.62	8
The lack/lack of up-to-date and high-quality resources in libraries	8.3	60.0	1.7	30.0	0	2.53	9
Overall and high volume of information	33.3	0	0	33.3	33.3	3.33	6
Uncertainty about the accuracy of web information	0	3.3	5.0	28.3	63.3	4.52	3
Failure to respond to the treatment cure (doctor, nurse, etc.)	1.7	3.3	6.7	16.7	71.7	4.53	2

of Members of Public Libraries.^[21] It seems that the most important reason for this incompatibility between results is the differences between statistical population, the type of disease investigated, and environmental facilities. In the current study, all participants knew about their condition and therefore required no further information on diagnosis. It also appears that, since participants in the current study were not informed regarding different treatment methods, they categorized information on different treatment methods as low priority. Patients preferred information on self-care which could help them improve their quality of life.

The findings showed that participants used "brochure and catalog provided by hospital," "other cancer patients," and "physicians and nurses" to meet most of their information needs. These results are similar to those reported by Kahouei et al. regarding health information needs of women undergoing obstetrics surgery^[7] and by Valero-Aguilera et al.,^[18] while there were differences between these results and those reported by Tariman et al,[13] Mayer et al. on comparison of survivors who do and do not seek information about cancer,[19] Feizi et al. regarding awareness level about warning signs of cancer, [20] the study by Zare Gavgani et al. on Information-Seeking Behavior of Members of Public Libraries, [21] and the study by Riahi et al. regarding health information needs of immigrants.^[16] The reason for this difference can be the fact that the participants in the current study spent long hours undergoing chemotherapy where their only source of information was other patients. There were also no other sources of information regarding breast cancer and treatment methods in the chemotherapy department of the target hospital.

The findings of the current study showed that high cost of information sources," "lack of response from treatment personal (physicians and nurses)," and "lack or trust in website information" were the most important information-seeking barriers among the patients. These results are similar to those reported by Latifiet al. regarding barriers of access of women with breast cancer to health information^[22] and the study by Milewski and Chen regarding barriers of meeting the information needs of diabetic patients. [23] However, these results were different than those reported by Nasrollahzadeh regarding information needs of pregnant women^[15] and Riahi *et al*. regarding health information needs of immigrants.^[16] The reason for this difference can be differences in the disease type and study population. For example, Nasrollahzadeh mentions time constraints as the most important limitation of their study of information-seeking behavior of pregnant women.[15] Furthermore, time constraints of oncology specialists making them unable to answer questions and there is a lack of patient familiarity with

websites related to breast cancer which led them to use websites with easy-to-understand content which lacked proper credibility.

The findings of the current study showed that participants had a positive attitude toward health information and consider the use of health information to be beneficial. They believed that health information can help them in "controlling their conditions," "adapting to their conditions," "stress and anxiety control" as well as "preforming their social roles" improving their "hopefulness." These results are similar to those reported by Leydon *et al.* regarding information-seeking behavior of cancer patients, [32] Jenkins *et al.*, [33] and Barzabadi Farahani regarding information needs of patients undergoing chemotherapy, [34] Mufunda *et al.* regarding diabetic patients, [35] Mayer *et al.*, [19] and Yan regarding information-seeking behavior on the internet. [36]

Limitations of the current study include lack of proper sources on information-seeking behaviors of female cancer patients in Iran. Fatigue and pain in patients and lack of cooperation from some of the patients' families were also among limitations of the current study. To reduce these limitations, researchers read the questionnaire carefully to patients and provided additional explanations when required. The strengths of this study included investigating female cancer patient population due to their important role in their own self-care and that of their family members.

Conclusion

The results showed that participants potentially seek to gather relevant health information. Therefore, if health information is presented to them in a useful format, it can help improve their treatment as well as help prevent breast cancer in others. This is due to the culture of sharing information and experiences in the society. It is worth mentioning that information sharing and transfer process can be managed using question—answering system to prevent sharing of wrong information.

Patients' lack of knowledge about credible and useful information sources regarding breast cancer reveals the need to making them informed in this area. Most patients are unfamiliar with credible and validated websites and media which is one of the most important reasons for not using these sources.

To remove these barriers, it is necessary to evaluate printed and electronic information sources regarding breast cancer and determine credible and validated sources. The information needs of patients should be fulfilled from various sources based on their level of skill and health literacy. Given these results, it is suggested

for easy-to-understand sources of information to be accessible to patients freely or at a low cost. Since these sources of information lead to better self-care among patients, the cost of their creation and distribution is justified due to reduced cost in the health-care system. To produce and evaluate easy-to-understand sources of information, it is possible to use the knowledge and expertise of librarians and medical information experts since their familiarity with various sources of information makes them the most qualified individuals for production and evaluation of information sources. The cooperation between these librarians and medical information experts as well as experts in medicine, nursing, and paramedical experts (due to their clinical knowledge and direct contact with patients) can lead to suitable results in producing quality sources of information.

The current study investigated health information-seeking behavior of female breast cancer patients to provide the necessary information for better planning and policymaking in hospitals and facilitating patients' access to health information. Therefore, we suggest that future studies should investigate cancer patients' motivations for seeking health information. It is also possible to use qualitative studies of health information-seeking behaviors to determine the depth of patients' information needs, leading to production and publication of health-related knowledge, and design of websites to inform the patients and influence their information-seeking behavior. The results of the current study are relevant for the current study population and care should be taken in generalization of these results to other populations.

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Conflicts of interest

There are no conflicts of interest.

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