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Using information sources by breast cancer women treated with mastectomy

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Abstract:

BACKGROUND: Awareness of sources of information of mastectomy patients has an important role in accessibility of reliable health information sources, thus, when they get information, they can be effective in the treatment and self-care. The present study aimed to identify the sources of information used by women underwent mastectomy.

MATERIALS AND METHODS: The current practical research methodology was qualitative, and research method was conventional qualitative content analysis was performed on 17 patients with breast cancer undergone mastectomy. The sample targeted two hospitals were selected based on criteria of Shaeid Mohammadi and the Persian Gulf and Omid Central chemotherapy in Babdar Abbas. Data were collected by face-to-face semi-structured interviews were conducted in winter 2015. Qualitative content analysis of data was performed at the same time of data collection.

RESULTS: Three themes were seemed (medical, interpersonal, and media) sources for explaining the sources of information searching. Subcategories derived from the content of medical (physicians, surgeons, and health workers of health facility centers), interpersonal sources (Family and friends, peers), and media sources (printed, electronic, and Internet).

CONCLUSION: Given the importance of information on women underwent mastectomy, and their priority in the use of medical sources, necessitates more attention of health system managers and planners in providing essential information and their accessibility.

Keywords:

Breast cancer, information sources, Iran, mastectomy

Introduction

In Iran and many countries, breast cancer is the second most common type of malignancy in women and the leading cause of death from cancer among women.^[1] Mastectomy is the most common treatment in which the breast with or without lymph node is removed. Women from cancer mastectomy experiencing surgery and physical defects, physical and psychological threats which can lead to psychological damage such as depression and anxiety, change in lifestyle, fear and worry about

body image, recurrence, and even death.^[2] Women with breast cancer are the largest group of female survivors of cancer. There is limited information about the long-term quality of life (QOL) in disease-free breast cancer survivors. However, research shows that the search for appropriate and quality information has been leading their ability to self-Care, and not only reduces the effects of these threats but also to cope with the disease, better interaction during and after treatment, reducing anxiety and mood disorders, better communication with family, the preservation of life, and a healthier life after surgery.^[3-6] The World Health Organization's key messages tailored

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to women with breast cancer awareness. one of the important worldwide health issues which WHO offers.^[7]

Whereas, women underwent mastectomy, staying underwent several treatment methods during the disease process are increasingly looking for information, so they control their symptoms and control treatment decisions.^[8] There are several ways for getting information, including doctors, nurses, TV, Internet, CDs, and other informed people. However, the significance and quality of information are of the factors which is effective on how to search and use of sources. Many studies have shown clinicians and health sectors staff are very important as the first level of communication with patients in the proper transmission of information.^[9,10]

In this regard, some studies have been published valuable results in the field of determining information sources about undergone mastectomy patients. Wolf in a qualitative researches which published in two parts: information needs of women who have undergone breast reconstruction (Part I: Decision-making and sources of information and art II: Information giving and content of information) concluded that: part 1: Women diagnosed with breast cancer treated by mastectomy can choose breast reconstruction. The information needs of women undergoing this procedure have only been addressed in the research literature to a limited extent. Women who had undergone breast reconstruction with a specific focus on their views on how they considered their information needs could best be met. A purposeful sample of eight women was recruited to participate in two focus groups, each lasting 2 h. It presents the emergent key themes regarding decision-making about mastectomy and reconstructive surgery and the sources of information perceived to be relevant when preparing for breast reconstruction. Sources of information perceived by the participants as being helpful included the surgeon, the breast care clinical nurse specialist, photographs, contact with other patients, written information, the Internet, a tape of the consultation and information videotapes. The breast care clinical nurse specialist played an important role in facilitating the process of receiving information. This study provides useful insight into how health care professionals can inform and prepare women for breast reconstruction.^[11] Part 2: Women diagnosed with breast cancer treated by mastectomy can choose breast reconstruction.

Focus on their views on how they considered their information needs could best be met. A purposeful sample of eight women was recruited to participate in two focus groups, each lasting 2 h. Framework analysis was used to develop an index of key themes and sub-themes which transformed the data into a structured record which facilitated systematic analysis.

It will present the emergent key themes regarding information giving and the content of information that women perceive as important when preparing for breast reconstruction. The process, delivery, and patient factors are presented in the category of information giving. Several subthemes are discussed concerning the content of information considered to be relevant. Those involved in imparting information to women about such surgery should be aware of the type of information that is considered relevant, the manner in which it should be delivered and timing factors that implicate on the process.^[12]

Nilsson (2014) has written in the same issue based on eight qualitative interviews with women who have had breast reconstruction with DIEP flap. The women were generally satisfied with the preoperative information they had received. The oral information given by a nurse varied greatly in quality and quantity. Preference emerged for more comprehensive information in writing, preferably with pictures, to be able to read at home. The women felt assured being able to call or E-mail a nurse whenever questions arose. The analysis revealed two themes, "feeling of satisfaction but also missing information" and "feel dissatisfaction and gratitude associated with breast reconstruction," with categories, information from the surgeon, information from the nurse, self-sought information, breast prosthesis usage, anxiety, pain, and self-esteem. Nilsson concluded that written information needs to be developed and improved.^[13,14] Some reports referred to the trust of searchers for finding needed information, especially in the field of breast reconstruction Internet sources and peers.^[6,15] In other studies, the Internet was mentioned as one of the main sources of information and low used sources have been reported radio and newspapers.

Moreover, the personal data (sources as doctors, healthcare workers, and healthcare providers) had priority. Family and friends reported another preferred information sources.^[6,8,13,15] reported also seeking information on the Internet, in-person or online support groups as sources of information).^[16]

Take on the research, shows that information sources used by women with breast cancer until this study has been a low consideration in Iran. Therefore, due to the lack of researches and the growing incidence and prevalence of breast cancer in Iran, this study seems to be necessary in this case. The need for this study due to recent policies of Women and Family Socio-cultural Council Women's equal right in enjoying will be increased the highest standards of health.

Among the most important strategies of these policies can refer increasing of women's central role in their care,

increasing women's access to information (in particular through the national and public media) qualified services and health care and proportional to their needs in different periods of life, and ameliorating the socioeconomic and cultural barriers affecting women's health.^[17]

Most Southern provinces of Iran come on with numerous problems and shortcomings in the field of health care which Hormozgan situation has difficult situation and worrisome than other provinces study on the information sources of the women in this area can provide valuable information for directors of information services and health information interventions to breast cancer.

Materials and Methods

The current practical research methodology was qualitative and research method was conventional qualitative content analysis. The reason for the qualitative method is the research gap and lack of empirical texts in the field of barriers of women's health information seeking behavior post mastectomy, especially in Iran. The operational research was conducted by content analysis which is the appropriate method to extract reliable results data and identify the themes of obvious and hidden text from the internalized data.^[18] Participants were selected based on the criteria and purposive method. Participants were selected based on the criteria and purposive method. Inclusion criteria were breast cancer patient and mastectomy for removal of all or part of a breast or two. During the study, there was no accurate statistics on the women underwent mastectomy referring in Hormozgan province with a list of them from the which performed on 17 patients with breast cancer undergone mastectomy (Of the 25 women identified six forward and two were withdrawn during the study). The sample targeted two hospitals were selected based on criteria of Shaeid Mohammadi and the Persian Gulf and Omid Central chemotherapy. Data were collected by face-to-face semi-structured interviews was conducted in Winter 2015.

Interview guideline for this study, the researchers experienced in the field of information behavior, related research study, and pretest interview have been set that it is a central question: "what sources did you use for accessing your data? Based on the answers were guided interview process." You mentioned in your speech that you would better understand by your doctors in medical conditions, please explain about this case, where necessary the participant was asked to clarify with an example. Interview's time was 45–75 min which matched later which was performed face-to-face in hospitals, physicians' offices and at home of the participants, they agreed with the recordings and based on the recordings,

interviews were typed in MS word processor software. Data collection continued until saturation was achieved. The key concepts and codes were put into sentences and paragraphs and classes created and finally, the themes were extracted.^[19] For evaluating validity and reliability of the data, Lincoln and Guba's indicators that is, were considered the credibility, dependability, confirmability, transferability. For reliability, were used investigator triangulation and constant comparison.^[20] So that, the devotion of appropriate time for data collection, usage of viewpoints of mastectomy surgeons in analysis and agreement with participants about collected data were used procedures for assurance of accuracy and strength of data. For the study of effectiveness, data have given two breast cancer surgery specialists and comparing their viewpoints and analyzing of their viewpoints which has much agreements have approved. Transferability potential also achieved by depth explaining. Before data collection, research ethics in research considered such as informed consent, anonymous, confidentiality, and privacy and participants' authority for leaving the study.

Results

Demographic of participants

Seventeen women of 37–65 years participated in this study. Their surgery time varied from 8 to 60 months. 16 of them were married, and all of them has child. Fourteen of them were housewife, 4 out of them with the weak economic condition, 10 persons have the average economic condition, and finally, 3 of them have the good economic condition.

Sources of information

Results showed that three sources for explaining of information search (medical sources interpersonal sources, and media sources) and interpersonal sources (physicians, surgeons, and health workers of health facility centers), interpersonal sources (family, relatives, and peers), and media sources (Sources printed manuals; brochures, books, magazines, photos; electronic media: radio, TV and Internet sources, Internet, and virtual networks [Table 1].

Medical sources

Most of the participants believed that medical sources are a primary reference and most reliable information sources. Proficiency, specialty, the experience of physicians, surgeons, and health workers are the most trustworthiness and priorities.

Physicians

Participants believed that the type of information needs is impressive in source selection. Physicians know better about questions of physical and health care. It cannot be risk in these areas. People will help based on their

Table 1: Classes and sub-classes of sources used by women underwent mastectomy

Sources of information	Sub-classes	Reasons for using
Medical sources	Physicians, surgeons, health workers of health facility centers	Reliability - Experience and expertise, better understanding of patient conditions, ability to communicate face to face
Interpersonal sources	Family, relatives, peers	Experience, low cost, feel more comfortable, face to face communication, availability
Media sources	printed manuals, brochures, books, magazines, photos	Convenient access, low cost, the possibility of readmission to the materials
	Electronic media: radio, TV	Ease of access and use, cheap, and fast
	Internet sources, Internet, virtual networks	Ease of access, cheap, and fast

experience, but physician guide doctors considering the patient’s condition. Patient 8 told that: “because of high blood pressure, I just consult for my diet with my doctor for assurance of diet.”

- Sometimes also searching for information is not only to obtain health information but also to validate it-was done. Participants know physicians’ viewpoints as main accreditation of knowledge and information from other sources to ensure the accuracy of the physician
- Patient No. 7 told that:”

I had heard from relatives that after chemotherapy, I could not get pregnant. My physician rejected this idea and after that I became happy. The physician can correct mistakes’ opinions.

- Experience of participants indicated that economic conditions also play a role in getting information, so that, patients with good economic situation believed receiving information has worth paying, and prefer to ask most questions from the physician
- Patient No. 14 stated that “the issue of breast reconstruction is very important, so I went to my doctor several times to have enough information to make the best decision I wanted my advice and...
- Patient No. 17 stated: While patients with low economic status and average preferred information sources less expensive to use. One of the patients stated that: “everyone must be his/her own doctor, it is not necessary for every problem to see a doctor and pay for visit.”

Surgeons

- Patients’ experiences showed that surgeons expertise, experience, and accountability of his position was directed patients for searching of particular information in the field of breast reconstruction When the women underwent mastectomy looking to learn to consider the pros and cons and take the most appropriate and best treatment decisions. Patient No. 2 said: “Although breast reconstruction is a purely personal action and decided to operation. I talked with several of the surgeons. Surgeons are quite special to look into the matter out. Their viewpoints helped me in decision making. Finally, I

decided in confidence to operate to reconstruction

- Health workers of health facility centers
- Patients believed that quality of relationship among health worker and attending physician has impact on their information seeking behaviours, and where patients have not easier access to their physicians, health workers, especially nurses considered as sources of occupational information in healthcare facility centers. So that patients tried to communicate with nurses receive their required information
- Patient Number 4 said “one of the nurses was a close friend to me in the ward, thus, and he was kind to every patient.... I had any questions about the medicine, nutrition, my illness, I ask the nurse.”

Interpersonal sources

The patient reported that if a resource cannot meet their needs, they will have replaced by another source. Lack of time Doctor and nonmedical responders to their emotional and psychological needs is the main reason for the use of other sources. They stated that, in the field of emotional and psychological needs, they relied on interpersonal sources.

Family and relatives

From the perspective of the participants, communication, dialog, and unburdening with spouse and relatives were the most important resource of health information and quietness that were effective in the nature of their savings in health behaviour. Patient^[12] stated that: “Not all detailed questions to ask your doctor. I talk with my husband... talking with them to-get quietness, I began to find that answer.” –Patient^[9] expressed that “friends have much impact... the same that regularly visit, and say that everything you need we are ready for helping, and say do not be sad...” in brief, and give me consolation.

Peers

Patients stated that information exchange with other cancer patients can be assistant their concerns and talk about common experiences with other patients. Patient^[10] stated that: “impairment is very difficult ... Every time I saw myself in the mirror I was crying. I was seen young women who had to lose their both breasts when I spoke

with them, it became normal for me my condition was Better than them, they were young, they lost their two breasts ... thus, "Patients also pointed out important role in giving information and guidance to new peer patients and believed this information is reliable, inexpensive and quick and experiences of peers might not be found in any official text. Patients^[16] stated that: " Before starting chemotherapy, a relative of my husband who has done chemotherapy 5 years ago, I wanted her to give me her experiences. things that she he told me, all of them were very helpful.

Media sources

Use one of the media sources were for searching for health information and sometimes were the most referable resource. However, the emphasis and the importance of using any media were different based on demographic characteristics, economic, and cultural life. This theme has three subcategories (print, electronic media, and Internet), respectively.

Printed materials

Patients stated the study of printed materials and manual or brochure as one of the most important sources due to the easy access and the possibility of readmission to them. They stated that the possibility of forgetting of instructions ad difficulty working with computer, their incentive increase in the use of manuals and brochures, unfortunately, many hospitals didn't offer this service. Patients (1, 2, 3 ...) in this situation stated that: "If before or after the operation, we receive the accompanying manuals from the hospital about kind and diet and medication use and postoperative care-how to do everyday activities.)," these can be a good source for some of our questions. Another example of seeking information from printed sources of sensitive information is such as sexual issues, that shame prevents search results from personal and interpersonal sources and printed sources in this field are applied and adequate. Patients (4, 11, 13, 15) stated that some interviewees believed that some questions exist exactly which cannot ask from doctors. Patients^[6,4,11,13] stated that perhaps most of us (Iranian women), we do not have a feel of convenience and intimacy and good relationship with our doctor. Patient^[2] stated that: "I got in trouble after mastectomy in relation to my sexual relationship... I was not comfortable to ask questions from the doctor or the mother, and my sister. I prefer to read books because book gives you intact information. The interviewees, in addition, the books, magazines, photos, stated especially in the field of breast reconstruction expressed the most applicable information seeking sources.

Patients^[2,6,12] stated that "Reconstruction of treatment has the same important of mastectomy.

Electronic sources

- The emphasis of Interviewees was on television programs, particularly health network and doctor greetings [Doctor Salam) more than the radio programs and the "The Education Channel" of IRIB was mentioned as a source of information seeking. However, there were Interviewees who were dissatisfied with the lack of television programs. "Patients^[1,13,15] stated we watch "The Education Channel" of IRIB, we get most of our information from this program... The good thing about this channel is that the experts and clinicians are in this channel and we have no problem about the reliability of their medical information. however, this channel rarely dedicated program on the subject of breast cancer." Patient^[5] declared that: "I was listening to the radio at home when I was working. Radio Provides good medical programs. They Speak clear and I earn much information from the information in this way."

Internet sources

- Interviewees considered Internet and the virtual networks because of the ease of access to information as a source of information. So that, younger Interviewees who have average and good economic status and well-educated, they have experience in the use of the Internet
- Patient^[7] stated that: "my colleague introduced me some Internet sites which has good materials in the case of breast cancer, surgery and ... in those sites I will ask my questions by E-mail and they answerd my questions"
- Patient^[12] declared that: "I read something about the type of feeding on the Internet sites which was very close to my doctor's recommendations. In order that, I don't pay for physicians' appointment, I decided to in the Internet for answering my questions"
- Some of the interviewees were considered that information available on the Internet is nonuseful and refer to these sources is a kind of wasted effort.

Patients^[3,10] stated that: "A lot of times when I search for something I do not find an answer for them." Most of the writings are not scientific and more of the databases' materials are copy of the other sites. A number of them said that virtual networks are the best place for sharing and gaining the information. They believed that the virtual network allowing them to search for needed information in day and night.

- Patient^[14] told that: "in Viber, we have a group called Survivors..." If I have questions, I will present in this Viber group and I got the answers instantly.

Discussion

The results of this study presented a new grand vision and the sources used after mastectomy for women

with breast cancer. What occurs is deduced from the experiences of women in their participation in this study, that is, they tend to receive that Information about health and health care because of the expertise, experience, better interaction, trustworthiness of medical sources (doctors, surgeons, and health staff).

The interesting point in this study is that, however, patients always are not successful in accessing their information needs of medical sources, however, in the use of information obtained from other sources of information, they emphasized on the accuracy of obtained information, and they tend to discuss it with their doctor. Perhaps, the reason for this trust to the doctor is that still believe “doctor knows best” is common among many patients. It is suggested to consider the quality and quantity doctor-patient relationship. This, ultimately, will affect the process of self-care. Studies of Schmidt *et al.*, Wolf, Yao *et al.* also showed that Women suffering from breast cancer introduce physicians, surgeons and medical staff as a credible and reliable resource of their information for breast reconstruction and physical care.^[9-12] In addition, in the words of contributors, the role of medical staff is a combination of emotional support and making aware, which emphasizes that not providing adequate information by the medical staff causes the need of information seeking from other sources, such as other people, books and Internet by the patients, and providing adequate and accurate information by the medical staff will give them the confidence. Therefore, it is suggested that the medical staff spend more time for listening to the information needs of mastectomy women and paying attention to their needs.

The results showed that the support of family and friends is undeniable both this and the supporting from of two directions (help in finding the information sources and psychological needs) is of particular importance, so that, they prefer to refer to this resource for getting emotional support and meeting their mental needs.

These results may indicate the inadequacy of the information received from doctors and medical staff especially in the field of psychological needs. In some studies, husband’s support has been mentioned as a facilitating factor in the better treatment of women with breast cancer.^[21,22] Hence, it is suggested to provide the necessary education for husbands and family of mastectomized women in support of care needs, which is a collection of information and health services and related activities designed to help patients and their families during treatment, follow-up and recovery. Deeper attention to the patients to the importance of human communication in providing information to form larger counterpart’s reveals.

Mastectomy women are willing to talk and share information with their peers, because, women with breast cancer, when they communicate with each other, sympathy, and widespread debate on the issues and their experiences. Therefore, there is a supportive environment for knowledge. This could be to facilitate and strengthen the strong point for self-care behaviours based on family-centered empowerment model and process of peer-based health information exchange for health promotion of Mastectomy women. Literature reviews represent an important and positive role in promoting peers in the exchange of information that plays a feeling of health, QOL, satisfaction with the received data from authentic sources and reducing symptoms of emotional crisis.^[23] Mostly, patients tend to use printed sources such as manuals and brochures to access applied information and self-care, they believe that receiving information in manual or brochure are cheaper, easier and more durable, and make them to never forget the doctor’s instructions and prescriptions and Unfortunately, these sources was not provided in hospitals and other health centers in the province of Hormozgan.

Attention to this important challenge is the focus of this study because the present study was done in one of the deprived areas of Iran, and more patients announced their economic status in poor and middle. Furthermore, because of high costs, they prefer less to visit their doctors and they try to replace by cheaper sources of information. In a qualitative study of Nilsson (2014) showed that the outcome of breast reconstruction was perceived positively, the women experienced a better QOL in daily life. The women were generally satisfied with the preoperative information they had received. The oral information given by a nurse varied greatly in quality and quantity. Preference emerged for more comprehensive information in writing, preferably with pictures, to be able to read at home. The women felt assured being able to call or E-mail a nurse whenever questions arose. The analysis revealed two themes, “feeling of satisfaction but also missing information” and “feel dissatisfaction and gratitude associated with breast reconstruction,” with categories, information from the surgeon, information from the nurse, self-sought information, breast prosthesis usage, anxiety, pain, and self-esteem. It was taken from participants’ experiences that they can easily search for information on individual communications is not possible, using printed materials are applied.^[14]

It is suggested that doctors and medical staff by inspiration of these findings is no doubt due to mastectomy and chemotherapy injury on topics such as sexuality and marriage and shame will prevent them questions, to show sensitivity and provide such

information as unattended planning to mastectomy women easier access to the information they need. Another finding of this study is to obtain information through the photos and images that showed the decision to have breast reconstruction easier. The results of other studies also reported these cases.^[14]

Women who have removed the entire breast or even just a part of them have a better body image of their changes by seeing photos and videos and are more confident in breast reconstruction.^[12]

According to viewpoints of the study population, the information presented in television and radio programs as an accessible and inexpensive media is not enough, and they expected much information with more detailed about diseases in these media.

It seems that women underwent mastectomy able to use health information received in this way for self-care and this can lead to the promotion of their treatments process. It is suggested that health and medical programs related to breast cancer in radio and television broadcasts predicted greater. Furthermore in other studies, the radio and television have reported less commonly used source of information.^[6,8,13,15]

Research also showed that despite the widespread influence of Internet technology and the speed of access to information by the media, patients, Patients are unable to make good use of this media and cannot help themselves and it is seldom used to obtain information. While on the other studies are mentioned the Internet as a primary source of information.^[16] The difference reported in this study and with other texts that information search by online sources further reported, the lack of valid medical databases and Persian language, information literacy limitation, exposure to the mass of information and use of the Internet age is not common.^[16]

However, most patients in this study were old and under diploma and diploma degree that this result was not unexpected. While in the studies of information seeking behavior in cancer addressed as online supportive groups as information seeking the source.^[24]

This difference can be as large as family and interpersonal relations in culture-related which prefer traditionally more interaction and relationship between oral and easily, without doubt, the depth and influence to be done. The virtual communications network is less emphasized. However, this study has limitations also one of the limitations is the lack of a systematic database of women with breast cancer after mastectomy in the Hormozgan province that could affect the study sample. The researchers frequent referring to hospitals, and

the Bandar Abbas Chemotherapy center tried to solve the limitations were mentioned. On the other hand, this study was conducted in the Hormozgan province which of deprived areas of Iran and its findings are not generalizable to other areas. Conducted similar researches in other contexts will provide possible match the findings of this research.

Conclusion

One of the main achievements of the study is the necessity of emphasizing on medical sources is the women underwent mastectomy. Fundamental changes in the structure of the health system are necessary to be done so that the culture of providing services with an effective emphasis on doctor-patient communication skills spread among doctors and medical staff. Furthermore, pay attention to interpersonal sources as a source of support and information available for searching can be an effective strategy to ensure patient health information. Although the findings cannot be generalized, but it can be the point of departure implement policies and strategies, Cultural and Social Council for Women and Family to increase women's access to information (in particular through the national and public media) health care services and qualified and tailored to their needs in different periods of life were affecting women's health. However, this study due to the qualitative nature has its strengths and benefits. Since understanding the experiences and perceptions of mastectomized women in the field of health information sources has a potential value in their care system, this is a very important and critical issue for health care providers. The qualitative findings of this research reflect the experience of mastectomized women living related to their health information sources in their own words and how they understand and interpret health information sources. Furthermore, considering that this research has been carried out for the first time in one of the most deprived provinces of the country in terms of services and training of the health system, its qualitative outcomes can support the attention of clinicians and health policy makers of the province and provide patients with these medical supplies in order to meet the health information sources along with medical treatment.

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Conflicts of interest

There are no conflicts of interest.

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