

## Postmastectomy Information Needs and Information-seeking Motives for Women with Breast Cancer

### Abstract

**Background:** Health information-seeking behavior is a key concept in the empowerment of women with breast cancer after mastectomy for self-care management. Thus, a real understanding of their information needs and their information-seeking behavior may open up new opportunities for their postsurgery cares. The current research was conducted to identify the information needs and information-seeking motives of women with breast cancer after mastectomy. **Materials and Methods:** This is an applied qualitative research. Samples included 17 women with breast cancer after mastectomy selected from two hospitals of Shahid Mohammadi and Persian Gulf and Omid Central Chemotherapy in Bandar Abbas. Data were collected using semi-structured interview on winter 2014 and analyzed using qualitative content analysis method. **Results:** Three basic contents were extracted including information needs related to mental health, physical health related to disease and personal daily activities along with their subcategories, and representing common experience and perception of mastectomized women seeking for health information. Furthermore, hope, self-esteem, return to life, and available social support resources were expressed as the main information-seeking motives. **Conclusion:** Considering research findings, mastectomized women need to receive information in wide range of health and thus pursue purposeful behavior. Hence, it is necessary that required actions and measures are taken by health-care authorities, especially institutions responsible for women health, to support and meet information needs of the patients considering their information-seeking motives.

**Keywords:** Breast neoplasm, information-seeking motives, mastectomy, need, women

### Introduction

Breast cancer is one of the prevalent cancers among Iranian women, and according to Iran Cancer Registry Center's statistics, its prevalence and incidence are increasing in recent years.<sup>[1]</sup> Mastectomy is one of the common treatments for this cancer, in which breast is removed with or without lymph nodes. Women who undergo mastectomy experience surgery physical defects and physical and psychological threats due to cancer which can lead to psychological trauma such as depression and anxiety, changes in lifestyle, fears and concerns about body image, recurrence, and even death.<sup>[2]</sup> However, researches indicate that perceiving information needs and meeting them lead to their self-care improvement and not only reduce the impacts of these threats but also lead to their coping with disease, better interaction during and after treatment, success in self-care, and having a good life after surgery.<sup>[3-7]</sup> Thus, paying attention to these patients' information

needs during postsurgery care period seems vital to reach to better outcome in the shortest time.

Some studies have reported valuable findings regarding information needs of women with mastectomy. Wolf studied information needs of mastectomized women in his qualitative study and found two contents of mastectomy and breast reconstruction. Subclasses of mastectomy content included decision-making on mastectomy, alternatives for mastectomy, and ideas of other physicians regarding mastectomy. Subclasses of breast reconstruction content included decision-making on reconstruction, reconstruction time, idea of other physicians regarding reconstruction, and time of making decision.<sup>[8]</sup> Beaver *et al.* conducted an experimental research on two groups of women with breast cancer aiming at investigating feasibility of information-giving interventions by nurses. The main information needs of case group

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included treatment, family impact, genetic risk, sexual attraction, side effects, social life, metastatic information, and treatment options.<sup>[9]</sup>

In other study by Ahmed *et al.*, information needs of mastectomized women for decision-making on breast reconstruction operation were studied. Their findings included the operation itself, feelings, and health of breast after operation.<sup>[10]</sup> Allowed and nonallowed activities after surgery, relationship with the spouse, relationship with others, psychological function, sexual desires, body image, and physical function were reported as information needs of women.<sup>[11]</sup> Some studies reported main information needs of women on health care including lymphedema, side effects of chemotherapy on body, and effects of drugs.<sup>[12]</sup>

Such studies indicate targeted behavior of individuals for meeting information need from different information sources and effective individual and contextual motivating factors in information seeking.<sup>[13,14]</sup> In studies, health information-seeking behavior triggers are mainly divided into two categories: individual and contextual. Individual factors include demographic characteristics, psychological factors, perceived self-efficacy, and health beliefs, and contextual factors can be enumerated as characteristics of society, social capital, and media attention.<sup>[15]</sup> In other research, hope for better life and participation in decision-making are mentioned. O'Leary *et al.* in their findings refer to the women's age as an effective factor so that younger women needed more information and sought for more information.<sup>[16]</sup> Belief in God and remembering individuals in worse conditions are other factors triggering information seeking in women with breast cancer.<sup>[17]</sup> Social support and emotional well-being are mentioned, and their findings indicate that people with less social support and better emotional well-being seek information more than people with higher social support and higher emotional well-being.<sup>[18,19]</sup>

A look at researches indicates that information needs and information-seeking motive in women with breast cancer have been less considered in Iran in research works. Thus, considering lack of research works and growing trend of breast cancer incidence and prevalence in Iran, conducting this study seems necessary. Considering recent policies of cultural and social council for women and family on women's equal right to the enjoyment of the highest health standards, necessity of this study becomes more evident. Enhancing central role of women in self-care, increasing access to information (in particular through the national and mass media), and high-quality health-care services to meet their needs in different periods of life are among major strategies of these policies (Women and Family Socio-Cultural Council, 2015). Implementing these strategies without achievement of research findings on the information needs and information-seeking motive of

women with breast cancer after mastectomy would not be associated with expected outcomes. Thus, due to research gap in Iran, the current research was aimed to identify the information needs and information-seeking motive of women with breast cancer after mastectomy. To realize this goal, qualitative study using semi-structured interview was conducted on women with cancer after mastectomy in Hormozgan Province. According to reports by the Ministry of Health and Medical Education, Hormozgan Province is one of the most deprived regions regarding access to medical and health services and interventions, and it is in the last rank in terms of development in health and medical issues in the country.<sup>[20,21]</sup> Conducting studies on information needs of women in this region and information-seeking motive can provide necessary information for authorities for health information interventions on breast cancer and eliminating information needs considering their motives and may provide a field of future research works in other regions.

## Materials and Methods

The current research is an applied work, and its methodology is qualitative. This method was selected to overcome research gap and lack of experimental literature in the area of information needs and health information-seeking motives of women after mastectomy in Iran. Exploratory and inductive approaches to qualitative methodology help detect hidden dimensions of the phenomenon. On the other hand, due to fundamental differences in different sociocultural contexts, the current research adopted qualitative methodology instead of quantitative theories and methods. Research operation was conducted by contractual content analysis. It is regarded as an appropriate method for extracting reliable results from textual data and identifying implicit and explicit contents from data classes. Participants were purposefully selected based on criterion 1. Inclusion criteria included having breast cancer and mastectomy as total or partial removal of one or both breasts. There was no exact statistics of mastectomized women in Hormozgan Province at the time of research. A list of them was prepared from Shahid Mohammadi and Khalij Fars Hospitals and Omid Chemotherapy Center in Bandar Abbas. There were 25 women identified that six women quit before research because of some physical and mental problems due to chemotherapy and two women withdrew during the research as the result of cardiovascular problems, and finally 17 women participated to the final stage. Data collection was done using semi-structured interview tool on winter 2014. Interview guide was formulated considering research goals, experience of researchers in information behavior area, studying related research works and pretesting interview from one of the participants. Its key items included "Which information did you need?" and "What did encourage you to seek for information?" Then, interview process was directed according to the answers.

During interview, exploratory questions such as “Can you explain more? What did you mean in this case? and Can you give an example?” were used for more information and clarifying materials. For example, one of the participants referred to breast reconstruction and she was asked, “you said that you needed to decide on reconstruction with awareness, can you explain more about it.”

Length of interviews was 45–75 min, which were implemented with previous call setting in treatment centers, doctors’ offices, or home of participants. Interviews were done face-to-face and were recorded with their consent and then transcribed in Word program. Data collection continued until data saturation. To analyze, interviews were transcribed and coded. Then, concepts and codes were put into key sentences and paragraphs, and classes were created, and finally, contents were extracted. For example, statements which reflected proper way of drug consumption or increased drug information were placed in drug consumption class. Statements referring to healthy food choice and food constraints were classed as food diet class. Moreover, finally, these subclasses were placed in more general class of physical care.

Lincoln and Guba indexes mean credibility, dependability, confirmability, and transferability were considered for evaluating reliability and validity of the data.<sup>[7]</sup> Investigator triangulation and constant comparison were used for validity so that allocating adequate time for data collection, using ideas of breast surgery specialists, and agreement with participants on obtained concepts were measured used for assuring accuracy and robustness of data. For investigating conformability, different parts of classes were given to two experts, and their ideas and interpretations were compared, and it was found that there is high agreement and they were confirmed. Transferability was obtained by deep description of data. Before data collection, ethical principles were observed in research such as written informed consent, maintaining anonymity, confidentiality, and freedom of participants for leaving the study.

## Results

There were 17 women aged 37–65 years participated in this research. Their surgery time varied between 8 and 60 months. Among them, 16 women were married and had kids. According to their demographic features, 14 women were homemaker, four women were in poor economic status, 10 women were in medium economic class, three women had good economic status, 10 women had degree below high school diploma, and four women had high school diploma, but three women had BA degree.

### Information needs

Results obtained from analysis of findings led to extraction of three contents: (1) psychological health, (2) physical health related to disease, and (3) individual–social activity [Table 1].

**Table 1: Information needs of women undergone mastectomy**

Kind of needed information	Subclasses
Related to mental health	Fear of failure and lack of breast - fear of death and the children’s loneliness - concern over self-status in future
Related to physical health	Diet - using drugs and health tools - breast reconstruction
Related to disease	The nature of the disease - treatment effects
Personal activities	Beginning the sexual relations - house works - exercise

### Psychological health content

Participants referred to a painful experience due to mastectomy, which threatened their psychological health. To cope with new conditions after operation and solve the problems, they needed to receive information about coping with such tensions as fear of defect and loss of breast – fear of death and loneliness of their kids – concern about their status in the future.

Experiences of participants indicated that considering patients had relative understanding about the disease, but they did not have proper mental image of their physical defect; thus, they were shocked after seeing their breast. A patient stated, “I touched bandage place, I did not know what I was waiting for? After opening the bandage, I just cried” (Patient 8). Another patient stated, “I say to myself why my breasts are not fit? Many areas in the body like heart, kidney, liver, etc., are operated, but no track of it is left. Why this has such inharmonic appearance? I look at my body and compare it with the past. It does not have any attraction anymore. Understanding this issue is very difficult to me” (Patient 3).

The other concern perceived in the statements of participants was fear of early death and thus destiny of their kids after mother’s death. Some of them stated that lack of awareness of survival chance exacerbates their mental disturbance toward death. Participant 2 said, “at last death comes to mind for the human, that time, anyone thinks of the fate of kids. For me, who still need are, it is important to know that until when I can play role as mother for them. How long will I live? Is there chance of survival at all?”

Most participants were unaware of their status in the future and described it as a concern. They stated that unawareness about recovery of the past strength reminds sense of disability and lagging others. One of the participants said, “all the time I was worry that lest these treatments and therapies prostrate me, disturb my life, one gets worry, does not know what will happen to her, to what extent the disease will be exacerbated?.would it be improved or exacerbated?” (Patient 10).



### *Physical health content*

Experiences of participants showed that information need on food diet, consumption of drugs, and health tools and breast reconstruction is essential to improve individual health (self-care). These three needs were conceptualized as subclasses of physical health need content.

Participants frequently pointed out that variety of recommendations sometimes confused them, and they required diet consistent with dietary restrictions, how to modify eating habits, healthy food choices, and proper nutrition before and after chemotherapy. According to a patient, “when even you have a cold, you should pursue a diet, cancer needs more strict diet. You have to eat with cautions...all the time you have to ask what is good for you, what is bad.” (Patient 5). Another patient said, “it is said that it is better to use sweet drinks before chemotherapy, thus we asked if we can drink carrot juice. How about other juices? How many hours before chemotherapy and how much should we drink?” (Patient 11). Meanwhile, some patients with background of special diseases needed the most accurate and detailed information for diet control. A patient stated, “now I follow high calorie diet due to cancer. But low blood pressure is very troubling to me, I take medicines for a long time, but the problem still persists...I do not know exactly what to eat, what to do to keep my blood pressure normal” (Patient 1). Participants with poor economic status stated that they did not feel information need due to high cost of diet and conflicts between their diet and family diet. “When I make food for the family, I have to eat it too. It is difficult to make two types of food all the time. It is costly” (Patients 4 and 6). Another participant stated, “in order to follow the diet, one should have good economic status. For example, the doctor advised to eat white meat, but I cannot buy it regularly, or fish meat has high cost. Thus, I gave over the diet” (Patient 9).

Most participants felt information need regarding way of drugs’ administration, interactions, how to adjust the doses, how to keep drugs, medications’ side effects, contraindications, and proper use of drugs. “How long should I use drugs? How long medication should be used in this dose?...” (Participants 17, 6, and 2). A patient stated, “immediately after taking Adriamycin I felt heart beating, I did not know if it is side effect of medications which I took or a heart problem happened to me” (Participant 12). Experiences of some participants with special diseases showed they needed information regarding secondary prevention in addition to information on drug consumption. A patient stated, “I asked about the drug (Metoral) which I already took can I use it now too? What should I do so that blood pressure does not cause complications for me?... How do I control it?” (Participant 4). Statements by some participants suggested the need for information to correct inaccurate perceptions and misconceptions and unrealistic

beliefs in the context of use of herbal medicines. “I had heard from many people that there is a strong medical reason for impact of herbal medicines, but our parents used herbal medicines, I was looking for boiled herbal medicines, because our disease is hard, and drugs and pills have side effects. Finally, we should seek other ways too” (Patient ...). Considering sensitivity of operation place and its closeness to underarm area, most of participants stated they did not have adequate information on using toiletries (Epilady, waxing and Gillette, creams and depilatory powders, deodorants). A patient stated, “it was important to me how to remove underarm hair. I previously used depilatory cream, can I use it now too? Is there no side effect?” (Participant 14).

Experiences of participants suggested that after several years following mastectomy, need for information on breast reconstruction was felt more. Reconstruction cost, the best time for reconstruction, types of reconstructive repairing and its success rate, and pre- and post-operative procedures were the main stated needs. A patient said, “I mostly asked would any problem occur to me after operation. How would be shape of my breast after operation? To what extent would it seem natural?” (Patient 7). Furthermore, patients attempted to have information about advantages and disadvantages of each option to choose the correct and safe restorative options. “My entire question whether from my doctor or my surgeon was about my constraints after surgery and its advantages” (Patient 2). Experiences of participants indicated that economic status and age also play a role in perceiving information need so that patients with poor economic status and older age did not feel need for information on breast reconstruction. “These operations are for rich people. My husband afforded mastectomy by lending and loans...what is the difference for me to know about breast reconstruction and its function!” (Patients 6, 9, and 15).

### *Disease-related needs content*

Due to perceiving cancer threat and increasing its control, participants pointed out that information need in subclasses of disease nature and medical complications is important.

Majority of participants did not know about factors affecting the development of disease. Of course, a few of them referred to such factors as genetic, lack of breastfeeding, improper nutrition, history of menstrual disorders, stress, and discomfort. However, they needed more accurate and reliable information about disease etiology and factors affecting its incidence for better understanding of the disease. “I asked my doctor about reason for incidence of this disease. No one suffered from this disease in my family” (Patient 16).

Etiologic information need for some participants was with motive of primary and secondary prevention for other family members. A patient stated, “since I had a daughter,

I always was worry about her. I frequently asked about the time for beginning mammography for her, or if I can prevent from cancer incidence in the family by controlling genetic factors” (Patient 13).

Most participants needed information about ways for caring location of lesions and symptoms of infection, lymphedema in early states after operation. “Well the newly operated patient does not have awareness about many things...after getting discharged from hospital we have to know what to do in order to prevent infection? How do we wash area of operation? Why drainage has changed color? It is our health, our body; we need to know what happened? Why is it so?” (Patients 8, 11, and 16). Participants also needed information about risk of complications of complementary therapies such as gastrointestinal discomfort, irregular menstrual cycle, immunosuppression, hair loss, and vaginal dryness. A patient said, “since I was single, some matters were very important to me. I constantly asked if complications are eliminated at the end of treatment period. Would be my menstrual cycle regular? Can I give birth?” (Patient 7).

*Personal daily activities*

One of the main contents emerged in this study was personal daily activities. Most participants needed practical information for clinical care at home.

They pointed out to information related to daily routine activities including time for initiating sexual activity, heavy and moderate motor activities, carrying objects, climbing stairs and walking, exercise, taking bath, and way of sleeping. One of the main needs, which was frequently repeated in statements of participants, was beginning sexual relationship after physical changes resulting from surgery. They believed that beginning sexual activity helps strength of marital relationships. Thus, they raised their information need implicitly. A patient stated, “I asked the nurse secretly about my condition...I asked if I can have sexual activity?” (Patient 12). Another patient said, “I frequently asked when I can go to kitchen. Which actions are not risky for me so that I can do my light activities? When can I take bath? I did not like to be dependent on others” (Patient 5). Some participants needed information about type of exercises and other physical practices. One of participants said, “I previously did tennis practices, I was worry about its impact on my health, and I wanted to know if I can still continue it? Does not it cause any problem to me?” (Patient 7).

**Information-seeking motive**

Results obtained from analysis of findings showed that participants sought for health information with different motives. Among seven extracted contents, hope and self-esteem were individual factors, and second chance and available social support resources were contextual factors of information seeking [Table 2].

**Table 2: Factors motivating information-seeking behavior in women undergoing mastectomy**

Contents	Subclasses
Hope	Belief in God - hope to recovery
Self-esteem	Feeling efficacy in coping with disease - participation in medical decisions
Return to life	Trying to have a healthy life - accepting new situation
Available social support resources	Family - peers

*Hope*

Two subclasses were extracted from this content: belief in God and hope to recovery. It represents shared feeling of participants to hope as a source of psychological and physical comfort and motive for information seeking.

Participants have stated in their descriptions that hope to God and mediums to make them close to God such as praying and devotion and resorting to Saint Imams helped them for managing health problems and promoting health. A patient said, “hope is very important, human being lives and survives with hope, and it is very important that a light twinkles in one’s life...I always whispered prayers. I believed that God helps me to heal. Thus, I tried to know my disease without any fear so that I can help myself easier” (Patient 8).

For many participants, hope to improve was considered as a savior event that would facilitate the promotion of health behavior skills. A patient said, “I kept telling myself, do not think I’m going to die, many people survived this disease with having surgery, science has progressed, new treatments are coming...I said my disease must be harnessed” (Patient 10).

*Self-esteem*

Self-esteem was perceived and experienced as increasing capability and being valuable feeling and an important motivation for active search of information in participants. Subclasses of feeling efficacy in coping with disease – participation in medical decisions – were conceptualized in this content.

Most of the participants mentioned that they themselves have the main role in coping with disease after God. According to a patient, “well, cancer is a bad illness, especially when you are told that you have to remove your breast...the 1<sup>st</sup> day I asked my doctor to say everything about my disease to me...I had an internal belief that the best person, after God, who can help me is myself. I searched much about my disease. If cancer knew me, it would never catch me...cancer has withdrawn.” (Patient 11).

Some participants believed that the requirement for ability to make decision is awareness, and unawareness eliminates

right of choice in medical and care issues from the patient. Thus, need for making decision on their treatment encouraged them to actively seek for information. A patient stated, “I said to myself that it is not possible to be indifferent...it is not wholly decision of doctor, I should also give opinion” (Patient 2).

#### *Return to life*

This content represents feeling and perception of patients about healing from breast cancer and death. Thus, participants actively seek for acquiring information to have healthy life and accepting new situation.

Participants stated in the condition when they viewed themselves in the boundary between life and death; mastectomy was the opportunity that returned them again to life. Thus, they attempted to protect this divine gift in the best way. A patient declared, “I feel that I’m a blessed patient. I felt totally well after surgery and chemotherapy. I’m not sick anymore...it is highly valuable to me. I asked question from all; I read various materials...because I want to have proper planning for protecting my health” (Patient 5). Meanwhile, some participants contemplated in their lifestyle before their illness and had understood facts about their past wrong lifestyle; thus, they attempted to compensate it. A patient expressed, “I got nervous for everything before my illness (even for material things), I was sedentary, I did not have any diet, but now I am not so anymore, I’m constantly very careful about my health, I always faithfully observe my diet, I do not repeat my past improper behavior...” (Patient 12).

Participants believed that they should accept their new situation for continuous and organized care so that they can act with more ability in self-care management. In this case, a patient told, “I said it is a disease, it has been treated and it will be, and if I want to extend it more, I just make myself weakened. Constraints after surgery are like a rule for us, I accepted them with awareness so that I deal with them easily” (Patient 14).

#### *Available social support resources*

Participants frequently referred to role of family and peers in active search of information.

Participants declared that family support, especially spouse support, is important. This support is more evident in acquiring information for transition from acute period to recovery and awareness of postoperation care. A patient stated, “my spouse support was very important to me, yes, it was very important and it has the main role” (Participant 1). The other patient said, “family help is very valuable. When I see my husband and children’s care for me after my illness, I feel more energized...they constantly care for me...they remind me about my medicines” (Patient 7).

Participants declared that reliance on their peers’ experiences is the main motive for information seeking so

that it facilitates achieving optimal and acceptable health level. A patient expressed, “talking with someone who is like you is very effective, it makes you soothing...I liked to ask anything that I did not know” (Patient 13).

## **Discussion**

Analysis of participants’ experiences indicated four emerged contents including information needs related to psychological health, physical health, information related to disease, and individual activities. This study aimed to describe information needs and information-seeking motives of the women underwent mastectomy. Findings suggest that since breast is strongly associated with feminine identity, womanhood, sexual desires, and physical and sexual attractiveness, loss of breast is interpreted as a traumatic crisis; the crisis that its emotional distress and alienation may proceed up to destruction of psychological health. Negative attitudes due to loss of breast, altered mental image resulting from defects, and the lack of knowledge about the destructive effects of mastectomy are interpreted as a traumatic crisis. Considerable part of this problem refers to the lack of information about resulting loss and subsequently inability in understanding mental image of breast defect and loss. It seems that patients want to have more control over mental distress resulting from this challenge by prognosis. A study on information needs and accessibility to appropriate information lead to reduce the threats including psychological trauma such as depression and anxiety, change in lifestyle, and fears and concerns about body image.<sup>[17]</sup> Thus, it is suggested that women be made aware by applying appropriate strategies and providing visual information, and it can have considerable impacts on reduction of anxiety and concerns resulting from physical defect, and also, it is recommended that specialists, oncologists, and other medical personnel, by providing visual information, inform women about their situation to help reducing anxiety and increase of mental health. The other preoccupations of women undergoing mastectomy are possibility of imminent death and consequently the risk of maternal and child care position. Since maternal role is a part of women’s identity in all cultures, women undergoing mastectomy want to control this crisis with awareness of survival chance and preserve their maternal role by keeping mother–child relationship, which is one of the strongest emotional relationships. It should be noted that death and the hope of survival are mental issues rather than physical, thus largely influenced by inclination, so it should consider the doctor’s role in encouraging patients. The doctors can be effective on the patient’s attitude toward her illness and increased self-esteem to be survived as well as playing her maternal role. Kim *et al.* in an exploratory study found that the main concern of mother undergoing mastectomy is concern about children care, their health status, and supporting them.<sup>[18]</sup> The other need of participants was concern about



their future status and loss of ability to do the works. Perhaps, this concern is associated with intellectual history of Iranian women regarding higher status of men, and they still believe in patriarchy in our country. There is a cultural belief that the man is allowed and can make decision for his life as he tends, whether he has healthy wife or a wife with cancer which has lost part of her abilities. This belief increased necessity for awareness of previous strength return in the participants so that they can retrieve their role as wife, while this subclass has not been referred in the reviewed literature. This difference in findings can be due to common beliefs regarding the woman status in Iranian culture. To this end, it is necessary that health-care providers offer necessary training to mastectomized women and their spouses given common beliefs in the society and by providing counseling sessions to spouses of mastectomized women; they were learned that cooperation, empathy, and their behaviors are considered as an important factor in the positive and effective confrontation with the disease for their spouses. Findings of the current study suggest that though participants perceived importance of diet, they were not sure about their nutrition way due to contradictory information and needed proper information. In reviewed literature, providing proper nutritional information has also been emphasized.<sup>[3-6]</sup> However, participants in low economic levels did not feel need for nutritional information. This finding was different from findings in other works. It should be noted that in information-seeking literature, economic status is regarded as one of the variables affecting information-seeking behavior so that individuals in lower economic classes either have lower need for information and seek less for it.<sup>[22-24]</sup> It can justify the difference because the current research was conducted in one of the deprived regions; thus, most participants declared their economic level as poor and medium. Due to the costs, they did not seek for the diet. Hence, considering the fact that being on a diet is considered as an important treatment option and often as the first-line treatment of patients due to fewer side effects, it is necessary that health system takes plans for welfare of low-income mastectomized women and conducts interventions to provide low-cost diet. Findings indicated that mastectomized women are not always able to use health information so that they reported the least information regarding prescription drugs and herbal medicines. Thus, need for awareness of information about prescription drugs and herbal medicines seems necessary for conducting precautions and predictive measures.

In the current study, lack of transparency on breast reconstruction for women undergoing mastectomy made problem for decision-making about breast reconstruction. In the research by Ahmed *et al.* and Wolf, this point was also mentioned.<sup>[8,10]</sup> The other important finding of the study was information need of participants regarding nature and complications of disease. It seems that familiarity with nature of disease can be effective in the

prevention of disease progression, reduced incidence of late consequences, reducing costs of treatment, and care for other family members.

In addition, need for acquiring information about treatment complications, familiarity of patients with symptoms, consequences and preventative activities, and patient-centered care seems necessary. Shea-Budgell *et al.* reported the main information needs of women on health care including lymphedema, side effects of chemotherapy on body, and effects of drugs.<sup>[23]</sup> Experiences of participants denote that they need practical information for return to ordinary life and self-care at home. Perhaps, it can be judged in this way that today only being alive is not intended by mastectomized women, rather they want to have an optimal qualified life so that they can do their daily activities. To this end, one of the main issues is sexual activities. Sexual relationship is an important part-of-care program in individual activity, which is influenced by psychological-mental and physiological factors, and has critical importance in such conditions. Allowed and nonallowed activities after surgery, relationship with the spouse, sexual desires, and physical function were reported as information needs of women in other studies.<sup>[11]</sup>

Impact of different factors on active information seeking is noticeable in the approaches adopted by the participants so that they focused on solving problems with reliance on God as an effective force and acted more actively for treatment. This finding suggests influence of Iranian-Islamic culture and religion on information-seeking behavior, and it can be argued that health information seeking can be a normative behavior. Results of the qualitative research work showed that religious concepts have considerable role in interpretation and perception of disease and coping strategies for mastectomized women. Leydon *et al.* referred to God belief as motivating factors for information seeking in women with breast cancer.<sup>[17,18]</sup> On the other hand, participants felt recovery and health after removal of acute symptoms of disease and sought for information actively to preserve their situation. Furthermore, participants believed in self-esteem as an internal and strong supportive force so that increased self-esteem in patient caused adopting preventive health behaviors and feeling effectiveness for informed decision-making. Rees and Bath mentioned individual factors triggering women information-seeking behavior as coping with cancer, recovery of control feeling, increasing self-confidence, and better decision-making.<sup>[22]</sup> Patients participating in this study considered mastectomy as turning point in their life and intended to adopt decisions for having healthy life and accept new situation. Analysis of participants' experiences indicates that family members and relatives have undeniable supportive role in encouraging positive health behavior support, coping strategies to adapt to new life conditions, and reduced psychological reactions. In other words, it can be said that available social support

acts as a shield against negative consequences of disease that influence compatibility indexes through physiological, emotional, and cognitive routes. Talking about issues related to disease in a noncritical and supportive space allows people to learn coping skills better. It can be a strong point for facilitating and promoting peer-centered health information acquisition and exchange and self-care behaviors based on family-centered empowerment model. Davis also referred to important and positive role of others in encouraging healthy behaviors. Some studies have pointed out social support and emotional well-being and showed that individuals with higher social support and emotional well-being have more information-seeking behaviors.<sup>[25-27]</sup>

## Conclusion

Meeting information needs of mastectomized women including a wide range of psychological and physical health, related to disease and personal activities, requires more serious and extensive attention of the Ministry of Health and Medical Education. To this end, it seems necessary to pay attention to information-seeking motives, which is a fundamental factor in active health information seeking. Although the findings are not generalizable, it can be used as departure point for implementing policies and strategies of cultural and social council for women and family on increasing women's access to high-quality health-care services and information suited to their needs in different periods of life and promoting information-seeking motives compatible to sociocultural conditions affecting women's health.

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## Conflicts of interest

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