

## Reaching out for the Truth; A Need Universal to Every Woman with Cancer: A Qualitative Content Analysis

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### A B S T R A C T

**Background:** One of the unmet needs in close association with the quality of life in women with breast cancer is the need for communication; therefore, the aim of the ongoing research is to elucidate the communication needs of patients with breast cancer.

**Methods:** The present study is a Qualitative Content Analysis covering a cohort of people including 20 patients, physicians and nurses who were selected from amongst clients and staff of Shohadaye Tajrish and Taleghani hospitals affiliated to the Shahid Beheshti University of Medical Sciences. Purposive sampling was conducted and continued until data saturation. Semi-structured interviews were used for data collection. All the interviews were recorded and transcribed into typed text. Analysis of data was done simultaneously applying content analysis as outlined and developed by Graneheim & Lundman (2004) using the software MAXQDA. The data trustworthiness was evaluated using the criteria developed by Lincoln & Guba.

**Results:** Two major categories were earned: “identifying sources of information”, and “the necessity of a training package”; while the major category of “the desire to know” was explored as the need marked by the breast cancer patients during cancer treatment process.

**Conclusion:** It appears essential to provide relevant information about the disease and how-to-care procedure as well as to identify the sources of information to meet the patients’ needs for their participation in treatment decision-making and optimal management of life. Also, nurses and healthcare staff are required to work out the care provision programs by prioritizing the informational needs of the patients.

**Keywords:** Breast cancer, Qualitative study, nursing, Education

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## Introduction

According to the latest report presented by Iran's Cancer Registry Center in 2009, as many as 7,582 cases of incident breast cancer were detected in women, with an age peak recorded at 50-55 years<sup>1</sup>. In accordance with the GLOBOCAN worldwide statistics, cancer incidence in Iran has been reported upwards of 85,000 new cases, which is estimated to hit a record high of 156,000 people in 2030<sup>2</sup>. Current advances in early detection and treatment of cancer have resulted in the fact that more than 68% of cancer patients survive more than 5 years<sup>3</sup>. The patients experience high levels of physical stress, psychological and social problems, including loss of womanhood and reduced sexual activity and problems in assuming the role of mother and wife<sup>4,6</sup>. Evidences indicate that during treatment and thereafter, these patients have a variety of unmet needs associated with the disease such as lack of information about survival, types of treatment, recovery, survival rate, prognosis of disease, time of return to work and daily activities and social life<sup>7-9</sup>. Moreover, most of them encounter serious problems in accepting and coping with their disease<sup>10,11</sup>. Therefore, knowledge, awareness and getting information related to cancer care have been reported as important factors in patients with breast cancer<sup>12</sup>. Park et al in 2012 in their study stated that the highest levels of unmet needs in women with breast cancer are in the field of information and the health system<sup>13</sup>. Many patients tend to receive more information about their disease when they become aware of diagnosis of cancer<sup>14</sup>. Studies show that patients' information about their disease prognosis is related to their choice of treatment. Patients who do not have information about their prognosis may be skeptical in choosing and accepting the treatment method (such as chemotherapy, surgery and radiotherapy). So, one of the reasons for which patient discontinue treatment is

their lack of knowledge about the diagnosis and its outcome. In other words, by increasing awareness of patient and family about therapy stages, mental preparation improves when unpredictable complications occur and anxiety is reduced<sup>14</sup>. Protiere et al. in 2012, in a qualitative study, mentioned the needs of cancer patients in four fundamental concepts: information needs about the therapy methods, places of care, medication and diet<sup>15</sup>. Another study to assess the health needs of migrants with cancer showed that the most informational needs of patients are access to information to achieve a healthier lifestyle and disease control and management; between these factors, the informational needs related to nutrition; physical activity and pharmaceutical information are among the most important factors mentioned by the patient<sup>16</sup>. On the other hand, patients and families need appropriate information about cancer care costs, including expenses that are paid directly by patients for medical care (out of pocket payments), copays and services that are covered by insurance<sup>17</sup>. Today, one of the main priorities for improving the health, safety, quality and efficiency of health care, is providing access for patients / people and their caregivers to continuous, timely, complete, accurate, low-cost and patient-specific clinical information<sup>18</sup>. One of the reasons that patients with cancer need information is to achieve goals such as participation in decision making, self-care and raising awareness of the potential benefits and harms of treatment and maintaining quality of life of patient and family<sup>19,20</sup>. Providing information tailored to the needs of patients by health professionals for patients and caregivers leads to increased patient satisfaction and quality of life<sup>21,22</sup>. Therefore, health professionals must design interventions aimed at holistic support of patients and their families in the search for independent health knowledge and adherence to it by understanding the motivations and preferences of patients<sup>16,22</sup>.

Considering the growing incidence of breast cancer in women in Iran and the importance of promoting health and quality of life, the need for information in these patients is an issue affected by many factors such as cultural, family and patient conditions, education, and economic factors and religious beliefs<sup>23</sup>. Therefore, this study was conducted to “explore the informational needs of patients with breast cancer”.

## Methods

This qualitative study is designed based on content analysis of Graneheim and Lundman<sup>24</sup>. Purposive sampling method was used in this study. Participants were breast cancer patients and health care providers from two hospitals of Shohadaye Tajrish and Taleghani affiliated with the Shahid Beheshti University of Medical Sciences. Patients participating in the study had completed conventional breast cancer treatment (surgery, chemotherapy and radiotherapy) and at the time of interview, they had referred to palliative care clinic of the Shahid Beheshti University of Medical Sciences Hospitals Shohadaye Tajrish and Taleghani for follow-up. Patients were aware of definitive diagnosis of breast cancer by specialist and were under treatment and had spent at least six months from the time of diagnosis and had the ability to speak Persian. Inclusion criteria for health care providers were that they were working in the care and treatment of patients with cancer and they had to have at least one year of experience in this field. Data were collected through semi-structured interviews. The participants were asked to identify “After exposure to a cancer diagnosis and knowing that you have cancer, what experiences have you had?”, “How much do you want to know about the disease?” and “What issues would like to know more about what issues? Who did you ask usually? “What experiences have you had in relation to this disease?” “And later proportional to the answers, deep questions such as” explain more about this?

“Were also asked. Each interview lasted 45 minutes on average. The interview time was identified by coordination and asking participants in a way that does not impair their daily schedules to have ample opportunity to speak and participate in the interview. The process of qualitative data analysis was done according to recommended steps of Graneheim and Lundman: 1. The implementation of the entire interview immediately after each interview, 2. reading the entire text to understand its overall content, 3. The determination of significant units and Primary codes 4. classification of similar Primary codes to in a more comprehensive classes, 5. Determination of latent content of data<sup>25</sup>. Therefore, immediately after each interview, their content was written by researchers at the word and then content was read several times and the primary codes were extracted, then codes were integrated and classified on the similarity and finally latent concept and content of the data was extracted. Credibility, Dependability, Confirm ability and Transferability was used to ensure the accuracy and reliability of qualitative data<sup>26</sup>. In this study, reliability was ensured thru researcher’s long-term interaction with the participants, checking up on their experiences, devoting adequate time to the interviews and making use of a wide range of participants’ experiences. However, an independent observer was swung into action to evaluate the reliability of the researcher. Also, the words of the participants were recorded, transcribed and reviewed by the participants and the expert observers in a bid to contribute to the measure of truthfulness of the research findings. For enhancing the transferability, the research reference documents were kept in a safe place. As well, the researcher tried her best to make it possible for other researchers to follow up on the research procedure by providing an extensive and step-by-step description of the research procedure. The researcher, however, investigated the transferability of her study by providing the findings of the

study to some readers and thus getting their approval. Covering a wide range of participants in terms of age, occupation and educational status was another attempt to allow the transferability of the findings to be evaluated and judged by others. Ethical considerations in this study, getting agreement of university and hospital officials before the start of the study, emphasizing on the confidentiality of personal information and confidentiality of data, explaining about their right to enter or exit from the study and completing an informed consent form and getting oral permission to record audio was included.

**Results**

In this study, 20 participants, 10 women with breast cancer, 5 oncology nurses and five doctors were interviewed. The age range of patients was 35-61 years, mean age was 43.36±5.97 years and all patients were married. Between 8-80 months was spent from primary diagnosis and they had different levels of reading and writing education to university education and had a range of different careers and most of them were housewives. In terms of clinical stages patients were at stage II III and IV. 1 person was main caregiver (patient’s daughter). 5 clinical nurses of clinic (3 women and 2 men) were caregivers in Shohadaye Tajrish and Taleghani hospital

(affiliated to Shahid Beheshti University of Medical Sciences) had a bachelor’s degree in nursing and were married. Also 5 physicians (1 general practitioner, 2 surgeons, 1 oncologist and one psycho-oncologist) were interviewed who had 3 to 21 months (average 10 months) history of working with breast cancer patients and the mean age of care providers was 36.43±5.97 years. As a result analyzing of the collected data , in relation to trying to surviving of breast cancer patients, the source of eager to know formed with two category “identifying sources of information“ , “the necessity of a training package“ that are provided in **Table 1**.

Most of breast cancer patients looking to learn from the treatment team due to lack access to adequate and reliable resources and lack of integrity in education, educational content and educational administrator, information needs are mostly about the disease and self-care issues such as the treatment of diseases and complications, prognosis, sexual problems, breast implants and also self-caring ways.

Identifying sources of information

In order to continue the process of treatment and improve quality of life, getting information about the disease was so important for them that to achieve these information they were referring to multiple sources, including professional sources (including nurses, nurse practitioners in family or anyone that

**Table 1: categories and sub-categories of Interviews analysis**

category	Sub-category	Main theme
identifying sources of information	Professional sources	the desire to know
	Unprofessional sources	
the necessity of a training package	Undefined person as Education administrator	
	Undefined educational protocol	

works in health profession) and non-professional sources (including amateur people and counterparts, informal information sources, such as internet or on-line media). For example, most participants stated that their main concern is facing with complications at home and lack of access to sources of information. In this regard one of the participants says: "The first day was very difficult, I did not know what to eat, how to eat how much i should eat... as if my mouth was blistered..... But there was nobody to call and ask" (**patient 6**).

#### **Obtaining information from professional sources**

Most patients in line with the need for obtaining information from professional sources, especially mentioned physicians as "the main source of information". "Neighbor says something patient in the next bed says something else. You know I want my doctor to tell me" (**patient 2**).

Participants also need to get information about the possibility of survival and improvement and progress of disease and hereditary being of breast cancer from professionals of medical team such as doctors and nurses:

"Doctor, how long will I survive? If all the treatment stages go well... there is hope for me to be better (treat)..." (**Oncologist 1**).

Another patient said: "I just followed my doctor and asked all items from the doctor and he explained to me" (**patient 3**).

#### **Receiving information from non-professional sources**

One of their needs is obtaining information and awareness of their situation so as soon as exposure to symptoms and diagnostic procedures, patients seeking information about their disease from different sources.

In this regard, Patient 5 stated, "Well I thought I'd better to have information about my disease, I start-

ed to collect data by whatever means. For example, I asked every doctor for any sign that I saw that Dr. this part of my body is like that, what's the matter (or what's wrong with it)?"

The majority of participants considered high workload and lack of time of doctors, lack of training of patients as contributory factor in obtaining information from unprofessional sources. 51-year-old patient under treatment underwent mastectomy, complained about the lack of information about adverse drug events (in this case tamoxifen) and insufficient education about the effects of drugs. "No one gave an explanation on tamoxifen when chemotherapy. When the doctor began ...my mouth abscessed..." (**patient 5**).

In other words, our study showed the willingness of patients to receive information from the doctor is more compared with the other members of treatment team so that in case of the lack of response from physician, patients would get help from nurses, Internet and peers.

One patient stated: "I wanna ask a lot of questions in my mind... the nurse have no time, doctor just comes above us, visits us, and goes. He\she doesn't stay to ask him\her my questions" (**patient 9**).

"My stomach (digestive system) didn't work for 7 days, I didn't know what to do...the nurse told... the nurse was busy too and when she saw I'm asking constantly... she gave me a sheet to read" (**patient 5**).

Another patient declared: "when my doctor comes, I always ask him\her questions... if the doctor doesn't answer, I will read it myself in books, or I tell my son to search in the Internet" (**Patient 2**).

Unprofessional sources that patients seek information from them were included newspapers, books and the Internet and normal people. "I find everything I want to know about the illness from the Internet" (**patient 3**).

Alternatively, another participant stated, “My son is a nursing student. I read his books about breast and breast cancer. I found that none of the cases in the books is like mine. My skin neither became orange nor niche. My breast was healthy” (**patient 2**).

Some patients were seeking answers for their questions from people who were in similar situations or passed it due to receiving inadequate and incomplete explanations from treatment team.

“My doctor didn’t tell me that I lose my hair. I asked the next bed how is your symptoms. He\she explained to me and told me to cut my hair” (**Patient 8**).

#### **The necessity of a training package**

Most participants believed because there was no specified administrator for education and lack of training protocols or inappropriate teaching methods, adequate information is not provided for patients. One of the nurses stated, “Most trainings are done in the form of pamphlet and we expect them to have a right decision by reading these contents, but many patient and even their family don’t have the ability to read and they don’t understand the written content” (**Nurse 4**).

One of the other nurses stated in this regard, “When the patient goes home after chemotherapy, he\she must be trained well about something. For example, if the patient has urine discoloration, he\she must know where to refer...” (**Nurse 1**).

Participants stated that education is integral part of care and for providing high quality care, standard educational content is needed: “Our most important problem is the lack of training... there is a little bit of learning content on the websites and books, these are not a good conclusion... it must be clear that whose duty to provide (learning content)...” (**Physician 1**).

One of the participants said: “Developing standard educational content to Patient is one of the main

concerns in the field of cancer and often treatment team faces with the challenges in this area. For example, Sometimes patients ask the nurse questions about the type of diet that doctor or dietitian may not be aligned with nursing education” (**Nurse 2**).

#### **Discussion**

This study was conducted to determine the need for information in patients with breast cancer. According to the views of the participants to continue with more quality of life, patients need information on issues related to self-care and health-related information (complications, prognosis, sexual problems, breast implants, etc.) from prestigious educational sources, especially the professionals of treatment team.

In line with the present study, the findings of Ankem et al in 2006 cited demands made by the patients as lack of information about care at home, information on physical activity, information related to method and lifestyle, as well as information about work and employment<sup>26</sup>. In another study, the most important informational needs of cancer patients were stated as knowing the symptoms, drug information, treatment methods, general information on health, and anatomy and physiology<sup>27</sup>. In addition, they noted that they need to have information, especially about the severity of their condition and treatment options and recovery<sup>28,29</sup>. Even with a strong need for information on breast cancer, evidence from patients shows that family caregivers also do not receive necessary information about the care for cancer patients at home<sup>25</sup>. The greatest need of caregivers was reported as lack of specialized knowledge about breast cancer and ways to care for themselves and their patients<sup>30,31</sup>. Studies suggest that most of cancer patients need to learn information from authoritative sources such as physicians to get their questions answered<sup>32</sup>. Also, the results of many studies show that the great need of breast cancer patients to

get information about disease and care, as well as the need for receiving education due to imperfection in education of treatment staff, led the patients to seek information from various sources including unprofessional sources. In line with our results, Riahi et al in 2015 showed that the quality of patient communication with health professionals may affect information behavior and where patients do not have easy access to their physicians or health care providers or if they do not trust treatment staff's expertise, they will be motivated to seek information from other sources<sup>16</sup>. The results of another study showed that lack of satisfaction with information provided by staff and also avoidance from stressor staff who deal angrily with patients when communicating with them are the primary driver of searching for information from counterparts and the internet<sup>33</sup>. On the other hand, families should know about history, definition, reasons, symptoms and factors that make the problem and related available theories to help patient with more knowledge.

In this study, patients noted educational support of physicians; the medical team is the most important factor to deal with treating complications. Even some patients wanted to get disease related information and information about complications of treatment from peers and patients who have experienced this disease. In line with the mentioned results in many similar studies, importance of effectiveness of supporting these patients has been stressed.

In line with the uncertainty in the manner and type of educating patients, participants stated that much of the information is presented in written and they are expected to make the right decisions regarding their health status by reading the content. However, many patients who refer to health systems do not have the ability to read and as a result, they will not understand health information for this reason, because of misunderstanding the care and treatment, they do not ask any questions<sup>19,34</sup>. If training uses

unspecialized terms and is explained with simple words and if it is provided with different teaching methods (individual and group) and by trained and skilled nurses, it will be effective in follow-up and continuation of the treatment process and maintaining quality of life. Therefore, it is suggested that in order to meet the informational needs of patients and provide better care, patient education should be based on individual needs assessments and identifying priority<sup>35-37</sup>. In the present study, most participants reported that despite their tendency to get information from treatment staff (physician and nurse), they did not receive adequate support from them due to the doctors' lack of time or limited communication with doctor and nurse. Thus, they were encouraged to receive information from unprofessional sources. Thus, the unmet needs of patients in the study were lack of receiving information from professional sources, as mentioned in the studies by Abdollahzadeh in 2014, and Gunshen in 2013. Despite the fact that significant proportions of information needs were not met, in some cases it is seen that patients do not show desire to get information and even they are dissatisfied of information that they receive; it seems that this is due to different barriers such as large number of patients and low number of staff and ignoring patient's willingness to receive information from physicians<sup>38,39</sup>. The sole limitation of the research was the small size of the population under study; thus, the generalizability of the results to different societies should be worked out with utmost discretion. In furtherance of the findings and obtaining more information on the theme of the research study, it is recommended to conduct the research on a large study sample and various groups of patients. To help struggling patients survive and provide comprehensive care, a number of suggestions are made: it is essential to detect organized collective efforts in order to remove the communication barriers. It is recommended that the educa-

tional needs of both the caregivers and patients to be examined as a matter of priority by the health-care team, including nurses, and use evidence-based nursing pattern in order to respond to the patients' questions and thus resolve doubts whatsoever. Therefore, by applying the findings of this study, the nursing educators shall pay more attention to teaching the patients as well as communication skills as part and parcel of the educational curriculum. Also, the nursing managers can resort to the results of this research and develop in-service education programs in an effort to contribute to a more favorable context for patients' education.

## Conclusion

The results showed that women need to get information for making decision on prevention, diagnosis and treatment of breast cancer. Awareness of the needs of patients in different stages of treatment and increasing awareness among patients and families can have a positive impact on recovery and quality of life. Patients prefer professional human sources among multiple sources of information in order to get information and meet their clinical needs. Consulting with peers and non-scientific sources have been also mentioned as other sources of information for patients. It seems that one of its reasons is doctors' lack of time and nurses-patient communication to provide information, so it is recommended to check and fix these barriers. In order to overcome barriers that prevent giving information to patients, identifying the information needs of patients and what they want to know can be helpful. Therefore, initially the specific concerns and questions of patients should be identified. Recognition of these interests should be performed separately and with regard to patients' attitudes, culture and mental conditions. Another important issue is how to educate the patient; less attention was paid to this issue and what is often emphasized in wards is simply to

provide education, but not its quality and efficacy. Therefore, the findings of our investigation regarding educational needs of patients with breast cancer, highlights the importance of having standard training instructions for the patient, as well as the evaluation and feedback of training results.

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