

RESEARCH ARTICLE

Informational Needs of Women with Breast Cancer Treated with Chemotherapy

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Abstract

Background: Research in the field of informational needs of breast cancer patients is scarce. In the few published articles, these needs were usually not satisfied. The main objective of this study was to evaluate satisfaction regarding informational needs in women with breast cancer. The long-term goal was to guide physician-patient communication to meet these needs. **Materials and Methods:** A survey with 21 questions was completed by 84 female patients receiving chemotherapy in a one-day hospital in Beirut, Lebanon. All patients were aware of their disease and agreed to participate in the survey. **Results:** The doctor was the major source of information for patients followed by media (radio and television). The level of knowledge of patients concerning their disease was proportional to the number of information sources. Women aged younger than 45 years, diagnosed during the last three months before the survey and certified from high school were less satisfied with information given by the oncologist. The missing information was in relation with the steps of the treatment after the chemotherapy regimen, the risk of a family member (sisters and daughters) of developing the disease and management of lymphedema. **Conclusions:** This study generated a scale for the degree of satisfaction of information received by women with breast cancer from their oncologist. The physician can use this scale to improve his or her skills of communication to patients and diminish their level of fear and anxiety.

Keywords: Breast cancer - information needs - oncologist - patient satisfaction

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Introduction

Breast cancer is the most frequent malignancy in the developed countries (Oskay-Ozcelik et al., 2007). Women with breast cancer are usually afraid, in denial, vulnerable and with inconvenient psychosocial status (Stephens et al., 2007). Informing the patient can diminish the anxiety and the feeling of insecurity (Graydon et al, 1997). However, 96% of women having a breast cancer have at least one type of information that is not satisfied (Erci et al., 2007). The major source of oncologic patients non-satisfaction is related to communication problem with their physician, particularly the lack of information received about their disease (Iconomou et al., 2002). Few studies were interested in exploring the degree of satisfaction of the needs of women diagnosed with breast cancer especially their emotional wellness (Erci et al., 2007). To our knowledge this is the first study evaluating these variables in women with breast cancer in Lebanon and the Middle East.

The aim of our study was to identify the unsatisfied informational needs of women diagnosed with breast cancer and treated with chemotherapy. These needs vary

according to different variables (age, time from diagnosis and educational level). The impact of this paper on medical professionals is to provide a standardized profile of these needs according to different variables and consequently guide the physician-patient communication in the best way.

Materials and Methods

Study type and sampling

This study is a cross-sectional study. The sampling was carried among female patients with breast cancer presenting to the one-day hospital of Hotel Dieu de France in Beirut to receive chemotherapy treatment. Data collection took place on all opening days between May 2009 and mid-September 2009. The inclusion criteria were: women aged over 18 years, aware of having breast cancer and with no history of a previous cancer. The awareness of diagnosis was assessed by reference to medical records, asking the nurse in charge and finally an open question to the patient to name the disease for which she is being treated. Only women who responded with the words "cancer" or "tumor" were included in the study.

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Methods

The patients who met the inclusion criteria were selected every morning by reviewing medical records. They were informed that their answers or refusal to participate in the study will not affect their care. They were also assured of anonymity and that all data will be destroyed at the end of the study. The questionnaire was completed by an interview during the perfusion of chemotherapy to encourage participants to respond conscientiously especially regarding sensitive issues. Information about diagnosis, stage of neoplasia and type of treatment were obtained from the medical records. The questionnaire was translated to Arabic during the interview. The average time for interview was 20 minutes.

Material

The questionnaire of our study was inspired from the Supportive Needs Screening Tool (SNST) and the Supportive Care Needs Survey (SCNS). Written agreements from authors of SNST and SCNS were obtained at the beginning of the study.

A pilot study conducted on a sample of 16 patients did not depict issues in comprehensibility of the questionnaire.

The questionnaire consisted of 6 sections dealing respectively with:

- i). Educational level, time since diagnosis and socio-economic status.
- ii). Sources of information used by patients to meet their information needs.
- iii). General knowledge about breast cancer (6 questions).
- iv). Overall preference for information (2 questions).
- v). Information needs
 - a). About the disease and treatment (9 questions).
 - b). Concerning the activities of daily living (3 questions).
 - c). About self-image and acceptance of the disease (4 questions).
 - d). Related to family and private life (5 questions).
- vi). Open question for women who want to add a need that was not mentioned.

Limitations

- i). The study was conducted in a single center.
- ii). Asking patients about their information needs might increase the importance of these needs.
- iii). Using the Likert scale might push patients to choose the average in each answer.
- iv). Women who were not aware of their cancer were not included in the study. They represent 23% of our target population.
- vi). A longitudinal study should be considered to better evaluate the changing needs at different times of chemotherapy.

Analysis

The analysis was performed using Excel (2007) and SPSS (Statistical Package for Social Sciences).

Our population consisted of 84 patients. Two patients refused to participate due to lack of interest. The

participation rate was therefore 97.7%.

Results

Population

The average age was 54.1 years with an age ranging between 30 and 74 years. 61.9% of women were aged between 46 and 65 years. 64% of the patients were diagnosed for over 6 months. 42% of women had their baccalaureate without further university studies and 39% were not college graduate. 62% were housewives and 67% had a Crowding score (number of people in household / number of rooms) greater than or equal to 1.

Sources of information used

The physician was a constant source of information for all patients. In the 2nd place were television and radio followed by the family doctor or a general practitioner in 54% of patients (Figure 1).

Knowledge about breast cancer:

- A set of 6 questions:
- i). Having breast cancer is contagious.
 - ii). The risk of developing breast cancer increases with age.
 - iii). Not having children is a risk factor.
 - iv). Taking hormone therapy after menopause protects from breast cancer.
 - v). An X-ray (mammogram) allows early detection.
 - vi). Only post-menopausal women should have a mammogram.

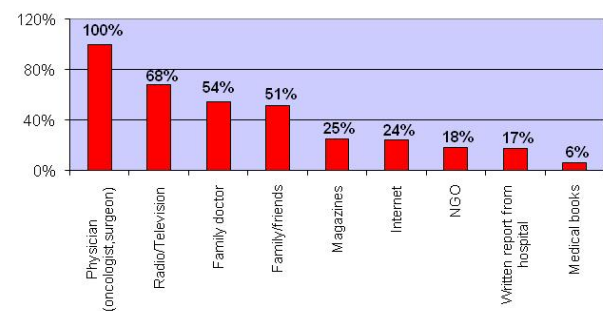


Figure 1. Prevalence of the Sources of Information Used. NGO: Non-governmental organization

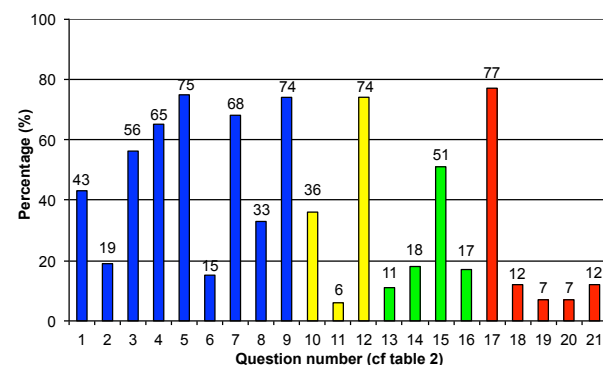


Figure 2. Prevalence of Information Needs with Average Above 3. *in blue: questions related to “disease and treatment”; * in yellow: questions related to “daily activity”; * in green: questions related to “self-image and acceptance of the disease”; * in red: questions related to “family and private life”

Table 1. Distribution of Scores on the Knowledge about Breast Cancer

Score on the knowledge about breast cancer (over 12)	% Of women
1 to 3	24
4 to 6	48
7 to 9	23
10 to 12	5

Table 2. Information Needs Survey

Question number	Information need studied
Disease and treatment	
1	Discussing further with the doctor.
2	Benefits of treatment.
3	Adverse effects of treatment.
4	Cause of the disease.
5	Risk of metastasis or recurrence.
6	Having a written report regarding my medical condition.
7	Being reinsured about the future.
8	Financing the treatment.
9	Follow-up after chemotherapy.
Daily activities	
10	How to be active in the process of treatment
11	Another doctor being aware of my medical condition.
12	Managing lymphedema.
Self-image and acceptance of the disease	
13	Interest in a psychology or psychiatry consultation.
14	Possibility of breast reconstruction.
15	Removable mammary prosthesis.
16	Presence of support groups (NGO).
Family and private life	
17	Risk of cancer for sisters / daughters.
18	Sexual implications of my illness.
19	Fertility.
20	Subsequent breastfeeding capacity.
21	Ability to use birth control pills after chemotherapy.

Table 3. Mean Likert Accordording to Age, Time Since Diagnosis and Level of Education

Information need	Mean Likert Scale Score
Age	
46-65	2.22
>65	2.01
Time since diagnosis	
<3 months	2.3
3 to 6 months	2
>6 months	2.2
Level of education	
No high school degree	2.14
High school degree	2.32
University degree	2.07

The answers to questions about knowledge were attributed zero (if the answer was false), 1 (if the patient answered "I do not know") and 2 (if the answer was correct). The mean score was 5.33 over 12. The median was 5. Women undergoing chemotherapy had a lower than average knowledge about breast cancer.

Knowledge of breast cancer based on the number of information sources used: The score increased from 3 (in women with a single source of information) to 6.15 in women using 4 sources of information about their disease. The knowledge about illness increased with the number of sources of information (Table 1).

Overall preference for the information

1. Load of information requested by the patient: This was evaluated by the following question: "do you want as much information as possible about your condition and treatment?" 33.3% of the patients requested information as much as possible. 2.4% of women preferred not to know anything about their health condition.

2. The need of answers to questions about illness: The patients were asked the following question: "Can I help you at this time and answer questions that concern your illness or health condition?" 38% of patients were in need of answers to questions and 2.4% were totally satisfied with their knowledge about their illness.

Satisfaction of information needs

A set of 21 items were studied in the questionnaire to assess the information needs (table 2). The women were asked to assign importance to each need according to Likert scale ranging from 1 (not a requirement, not applicable), 2 (satisfied need), 3 (moderately satisfied), 4 (poorly satisfied) to 5 (unmet need). The overall preference for information was also assessed by the Likert scale of 5. We considered any need with an average above 3 as an unmet need.

The answers were studied according to age, time since diagnosis and level of education: Women aged less than 45 years, diagnosed between 3 and 6 months and had their baccalaureate without a university degree showed the highest average of information needs. The average was less than 3 in all age categories (Table 3).

The major information needs were related to the risk of cancer in sisters/daughters, the risk of recurrence and metastasis, the follow-up after chemotherapy and managing lymphedema (Figure 2).

Discussion

Several studies revealed that young women having cancer have more often unsatisfied needs than men and older patients (Graydon et al, 1997; Ozkay-Ozcelik et al., 2007). In our study, women aged less than 45 years were less satisfied about the quality and quantity of information that they received. They disclosed more easily their needs when compared to older women (Sutherland et al., 2007).

Women recently diagnosed (less than 3 months) presented a higher need of information. The majority of patients have multiple and complex needs at diagnosis

(Piggot et al., 2009). We noted an alleviation of these needs after three to six months. The patients feel more secure because they were under treatment and were adapted to their chemotherapy and its side effect. The recrudescence of these needs after six months could be attributed to the decrease of psychosocial support provided by the family, friends and physician or the appearance of new needs. A Malaysian study showed that breast cancer patients on chemotherapy have high levels of informational needs with no significant differences in information needed at first cycle as opposed to fourth cycle (Lei et al., 2011).

Women who had their baccalaureate had more informational needs than women who were not graduated because they expressed themselves more easily (Erci et al., 2007). College graduated women were the most satisfied concerning the need of information. Many hypotheses could explain this phenomenon including the access to different sources of information, better cultural background and a better self-expression in front of their physician (Piggot et al., 2009). Ungraduated women were mostly worried about the treatment fees while college graduated women were interested to know more about mammary prostheses and support groups.

The physician represented the constant source of information for the patients. The latter expressed during the interviews how much they appreciate the efforts of their oncologist and how much they trust him. Television and radio programs represented another source of accessible and free information using an easy vocabulary. They were ranked in the second position as source of information in our study with 68%.

In our society and when diagnosed with cancer, the patient usually consult his family physician or a general practitioner. They came in the 3rd place as a source of information for the patients.

The information given to patients having breast cancer decreased the level of anxiety and the feeling of insecurity (Vogel et al., 2008). 80% of women asked for more information and more than third needed answers to questions concerning their disease. Despite the diversity of information sources, women had unanswered questions concerning their disease.

The received information about the risk of sisters and daughters to develop a breast cancer was judged insufficient (77%). Those women were afraid that because of genetics factors their relatives might develop cancer. This need was not satisfied by the oncologist probably due to the lack of onco-genetic consultations in Lebanon making the evaluation of risk to develop cancer impossible.

Asking to be better informed on the risk of metastasis and/or recurrence of cancer and the steps following the chemotherapy represented a major need in respectively 75% and 74% of women in our study. The patients need a treatment road map (Ozkay-Ozcelik et al., 2007), which can be a part of the information that can decrease the fear of those women from the future.

Regarding clinical implications, this study confirms a lack of communication in the Lebanese population between the oncologist and female patients with breast cancer. Practically, to counteract this phenomenon, the

physician can use this scale to ameliorate his skills of communication with his patients and diminish their level of fear and anxiety based on concrete and standardized survey.

In conclusion, although information for cancer patients is crucial for a better quality of life, many physicians underestimate this need. Women with breast cancer were not satisfied from the quality nor quantity of information they received from their physicians. Our survey represents a screening tool for the need of information in women with breast cancer. The use of this survey can help the oncologist to identify the needs of his patients precociously and adopt a targeted approach to answer them.

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