

Informational Needs among Women with Newly Diagnosed Breast Cancer: Suggested Nursing Guidelines

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Abstract

Background: Women with breast cancer require information to help them manage their illness, it assists patients in making treatment decisions and managing immediate effects of treatment. **Aim:** To identify informational needs among women with newly diagnosed breast cancer and to design a suggested nursing guidelines. **Setting:** This study was conducted at the outpatient clinic of Sohag Oncology Institute and Sohag University Hospital. **Sample:** A convenient sample of (100) adult female patients diagnosed with breast cancer undergoing breast surgery, radiotherapy or chemotherapy the age of patient ranged between (18-65) years old during period of 6 months. **Tools:** The tools were used for data collection included: An interview questionnaire, Toronto informational needs questionnaire of breast cancer. The suggested nursing guidelines was developed by the researcher. **Results:** The present study revealed that about (83%) of the studied patients had unsatisfactory level of knowledge regarding breast cancer. There was a statistically significant difference among chemotherapy & surgery group between total information needs and educational level. **Conclusion:** Women with breast cancer lack information especially about their disease, treatments and examinations they are undergoing. **Recommendations:** Establishment of specialized resource centers in different governorates of Egypt, rural and urban areas for meeting informational needs among women with newly diagnosed breast cancer.

Keywords: *Breast cancer, Informational Needs, Women&Toronto Informational Needs Questionnaire.*

Introductions

Breast cancer is the most common cancer in women in most countries and the leading cause of cancer-related death in women worldwide. The incidence of breast cancer worldwide is predicted to rise to 2.3 million by 2030, learning what patients want from their healthcare providers is an important step in addressing their concerns and meeting their psychosocial needs (Harding *et al.*, 2013).

Determining the stage helps determine the best way to contain and eliminate the breast cancer. Stage 0 & 1 represent the earliest detection of breast cancer development. At Stage 0 and 1, the cancer cells are confined to a very limited area. Stage 2 And Stage 2A is still in the earlier stages, but there is evidence that the cancer has begun to grow or spread. It is still contained to the breast area and is generally very effectively treated. Stage 3 A, B, And C is considered advanced cancer with evidence of cancer invading surrounding tissues near the breast. Stage 4 indicates that cancer has spread beyond the breast to other areas of the body (Smeltzer *et al.*, 2014)

Breast cancer and its treatment cause emotional trauma and health complaints. These lead to supportive care needs in some patients, while others are more able to cope with these consequences

themselves. To be able to address these needs, it is important to identify patients' needs at the time they arise (Büchi *et al.*, 2013).

Research studies on information needs and information-sharing in patients with cancer have been increasing steadily in the past 3 decades. These studies relating to patient information-sharing were aimed at improving patient education and ultimately increasing patient participation in health-care decision-making (Tariman *et al.*, 2014).

Today, understanding is growing about the importance of involving cancer patients in decision-making about their care with that understanding comes the need for additional information on diagnosis, prognosis, and treatment options to support patients and their families in making informed decisions (SheaBudgell *et al.*, 2014).

Information seeking has been demonstrated to play a critical role in individuals' efforts to cope with the disruption of the quality of life associated with cancer diagnosis and treatment. Obtaining information, particularly regarding prognosis and treatment, remains a major area of need for individuals with cancer (Nagler *et al.*, 2010). In order for information to be useful, there is a need to understand the nature of information that patients and their partners require (Kassianos *et al.*, 2016).

Significance of the study

An estimated number of patients with breast cancer in Egypt 2015 are 19411 patients and 19105 in females according to Results of the National Population-Based Cancer Registry Program. There were 146 patients diagnosed with breast cancer in Sohag University hospital (Sohag Hospital Record,2014). Knowledge of what women need at different points in the course of treatment of breast cancer methods can only come from asking the women themselves.

Aims of the study

This study aimed to identify informational needs among newly diagnosed breast cancer patients, design and implement suggested nursing guidelines.

Subjects & Methods

Research Design

A descriptive research design was utilized in this study.

Setting of the Study

This study was conducted at the outpatient clinic of Sohag Oncology Institute and University Hospital

Study Sample

A convenient sample of (100) adult female patients newly diagnosed with breast cancer undergoing breast surgery, radiotherapy or chemotherapy who are willing to participate in the study, mean age \pm mean SD was 51.23 ± 13.71 years during period of 6 months were included in this study.

Sample size using power analysis

Sample size was estimated with statistical program (Mini tab 17) and determined according to this equation:

$$Ss = \frac{Z^2 P (1 - p)}{C^2}$$

$$\text{Where } Z = 1.96 \quad c = 0.08 \quad p = 0.5$$

$$\text{New ss} = \frac{ss}{(1 + ss - 1)}$$

$$(\text{Pop})$$

(Pop) is the population = 250 , New ss = 94

Minimal required sample = 94

Study Tools:

Data of this study was collected by using the following tools:

Tool (I) : A structured interview questionnaire

It was designed by the researcher based on literature review, including two parts:

Part I : Included demographic data items as: (age, educational level, marital status, residence and occupation) .

Part II : Included medical related data items as: (duration, stages, treatment of disease, type of tumor, family history and nature of complaints) .

part III : Included knowledge about breast cancer, there were some opening questions as: (definition of breast cancer, definition of radiotherapy and chemotherapy and there were other closed questions as: (source of information, causes, treatment , care after operation, different surgeries, wound care after operation and complications for different breast cancer treatment.

Tool (II) : Toronto informational needs questionnaire of breast cancer

It was developed by Yi et al., (2007) to elicit women's perception of their informational needs related to their experience of breast cancer. Toronto questionnaire was translated into Arabic language for easily understanding by women. Toronto questionnaire comprised of a 52-item, measuring the following five subscales of informational needs: disease, treatment, investigative tests, physical and psychosocial needs.

Scoring System

Each item was scored as a 5-point Likert Scale as: 1 = not important, 2 = slightly important, 3 = moderately important, 4 = highly important, and 5 = extremely important. statistical presentations of data was derived from collapsing the original scale to 3 scale: 1 = not important + slightly important, 2 = moderately important and, 3 = highly + extremely important. Less than 50% is considered low important, 50% to 70% is considered moderately important, more than 70% is considered highly important. Total score with minimum of 52 and maximum of 208, the higher scores represent higher information needs

Scoring system of the present study about knowledge about breast cancer

It contains 9 questions the scoring process of it was: each correct answer took 1 score and zero for incorrect answer.

The total score was divided in to two levels:-

- Score less than 50% was considered unsatisfactory.
- Score above 50% was considered satisfactory.

Suggested Guidelines:

It was designed by the researcher from literature reviews based on patient's assessment informational needs and covers definition, stages of breast cancer, treatments, tests, breast cancer modalities and importance of breast surgery, radiotherapy and chemotherapy management and follow up. **American cancer society, (2016)**

Methods

An official approval and administration permission were obtained from the Dean of Faculty of Nursing at Sohag University and the head of the outpatient clinic of Sohag Oncology Institute and University Hospital to collect the necessary data,, an oral consent was obtained from patients to participate in the study and the nature and purpose of the study

were explained to them, confidentiality and anonymity were assured.

Field work

The interview questionnaire sheets were filled by researcher while patients at the outpatient clinic of Sohag Oncology Institute and University Hospital in the morning. Purpose of the study was explained prior to elaborate the questionnaire tools. Each patient involved in the study was interviewed to answer the Toronto informational needs questionnaire tool in the morning. Sampling was started and completed within 6 months from December 2015 till June 2016. Each patient had a copy of suggested nursing guidelines and had been explained for her, and covers definition, stages of breast cancer, treatments, tests, breast cancer modalities and importance of breast surgery, radiotherapy and chemotherapy management and follow up.

Content validity and reliability

It was established by panel of five experts in the field of Medical Surgical Nursing Specialty who reviewed the instrument and nursing guidelines for clarity, relevance, comprehensiveness and applicability. The content validity of this tool was checked by expert professor in medical surgical nursing and correction was carried out accordingly. Then the final form of tool 2 Toronto scale was designed and tested for reliability by using internal consistency for the tools measured using cronbach test, the tool proved to be reliable (cronbach's Alpha = 0.96).

Pilot study

Pilot study was conducted on 10% of the study sample (10) women in a selected setting to evaluate the applicability & clarity of the tools. According to this pilot study, the required modifications were made. Those patients who were involved in the pilot study were not included in the study.

Statistical design

The collected data were tabulated and statistically analyzed to assess informational needs among women with newly diagnosed breast cancer under study as regards the various variables by computer program SPSS" ver 16" Chicago USA Data expressed as numbers and percentage, using likelihood ratio to determine significant for the group.

$P > 0.05$ non-significant.

$P \leq 0.05$ significant.

$P \leq 0.001$ highly significant.

Ethical considerations

The study was approved by an institutional ethics committee.

- An oral consent was obtained from patient to participate in the study after the nature and purpose of the study were explained.

- The researcher initially introduced herself to all optional subjects and she was assured that the collected data would be absolutely confidential.
- Patients were informed that participation is voluntary and that they could withdraw at any time of the study.
- Confidentiality of the patients data was ascertained. Confidentiality and anonymity were assured. Then, through this patient interview, baseline data was obtained from the studied patients to fill in Tool I and Tool II.

Results

Table (1): Distribution of demographic characteristics of the studied patients (n= 100).

Items	No	%
Age:(years)		
18 - < 35 years	18	18
35 - < 50 years	44	44
50 - < 65 years	38	38
Mean \pm SD	51.23 \pm 13.71	
Educational level		
Illiterate	60	60
Basic education	20	20
Secondary	6	6
University or higher	14	14
Marital status		
Single	11	11
Married	60	60
Divorced	3	3
Widow	26	26
Residence		
Rural	34	34
Urban	66	66
Occupation		
Working	13	13
Not working	87	87

Table (2): Distribution of medical data of the studied patients (n= 100).

Items	No	%
Duration of disease		
< 1 year	100	100
> 1 year	0	0
Stages of diseases		
Stage 0	0	0
Stage 1	22	22
Stage 2	35	35
Stage 3	32	32
Stage 4	11	11
Types of treatment modalities		
Chemotherapy	40	40
Chemotherapy & surgery	5	5
Radiotherapy	14	14
Surgery	41	41
Types of tumor		
Spread	20	20
Non-spread	80	80
Family history of cancer		
Yes	59	59
No	35	35
Don't know	6	6
Nature of complaints at the first time		
Pain	2	2
Lump in a breast	54	54
Pain with lump in a breast	42	42
Lump in abreast with nipple discharge	2	2

Table (3): Assessing knowledge of the studied patients about breast cancer (n= 100).

Items	No	%
Definition of breast cancer		
Correct	40	40
Incorrect	60	60
Source of information		
Neighbors	18	45
Friends	5	12.5
TV	23	57.5
Doctor	13	32.5
Causes of breast cancer		
Correct	1	1
Incorrect	99	99
Treatment of breast cancer		
Correct	65	65
Incorrect	35	35
Type of treatment		
Surgery	57	87.7
Radiotherapy	42	64.6
Drugs	19	29.2
Breast cancer care after operation		
Correct	2	2
Incorrect	98	98
Breast cancer different surgeries		
Correct	2	2
Incorrect	98	98
Wound care after operation		
Correct	1	1
Incorrect	99	99
Definition of radiotherapy		
Correct	10	10
Incorrect	90	90
Definition of chemotherapy		
Correct	33	33
Incorrect	67	67
Complications for different breast cancer treatment		
Correct	11	11
Incorrect	89	89.0

Table (5): Total informational need according to Toronto scale for the studied patients (n= 100).

Items	No.	%
Disease		
Low important	2	2
Moderate important	12	12
High important	86	86
Examination		
Low important	5	5
Moderate important	30	30
High important	65	65
Treatment		
Low important	1	1

Items	No.	%
Moderate important	7	7
High important	92	92
Physical:		
Low important	0	0
Moderate important	36	36
High important	64	64
Psychosocial:		
Low important	0	0
Moderate important	40	40
High important	60	60

Table (8): Relation between demographic data of the studied patients and the total informational needs (n= 100).

Items	Age (years)		Educational level		Marital status		Residence		Occupation	
	F-value	P-value	F-value	P-value	F-value	P-value	F-value	P-value	F-value	P-value
Chemotherapy	1.889	0.166	0.259	0.773	1.780	0.183	0.428	0.517	0.387	0.538
Chemotherapy & surgery	0.332	0.605	10.499	0.048*	1.676	0.286	0.466	0.544	10.499	0.048*
Radiotherapy	2.544	0.124	1.287	0.315	2.008	0.182	0.024	0.878	2.623	0.131
Surgery	0.638	0.534	0.373	0.691	0.941	0.399	1.282	0.264	1.330	0.256

Table (1): showed that the mean age of the studied patients was 51.23 years. Also, 60% of them were illiterate and married. It was clear that about more than half (66%) of them were from urban areas, and only 13% of them were employees.

Table (2): showed that (35%) of the studied patients were in stage 2 of disease, regarding types of treatment modalities (41%) of the studied patients underwent surgery, and the majority had non spreading tumor, it also shows that more than half of the studied patients (59%) were having a family history of cancer and had lump in a breast at the first time (54%).

Table(3): demonstrated that about 60%, 99%, 98%, 98%, 99% & 90% respectively of the studied patients had no information regarding definition, causes of breast cancer, care after operation, different surgeries, wound care after operation and definition of radiotherapy respectively, Also, it was found that more than half of them 57.5 % their source of information was T.V.

Table (5): showed that (86% & 92%) of the studied patients had high important information need regarding to disease and treatment. 65%, 64% & 60% had highly important need of information regarding to examination, physical and psychosocial parameters of Toronto scale.

Table (8): showed that there was a statistically significant difference between chemotherapy & surgery group regarding total information needs and educational level $P < 0.05$ and there was a statistically significant difference between total information needs and occupation $P < 0.05$.

Discussion

Part I: demographic characteristics

The present study clarified that the mean age of the studied patients was around fifty years. The majority of patients were married and not working. These results approximately congruent with **Bei et al., (2015)** who studied the factors in the prioritization of information needs among breast cancer patient and mentioned in their results that the mean age of participants was around fifty years. Also, **Polly et al., (2011)** in their study mentioned that breast cancer is the most common cancer among women with age around 50 years. **Tracee, (2009)** supported that study finding when mentioned that breast cancer risk increases with age. **Dolinsky, & Hill-Kayser, (2008)** concluded that the most important risk factor for development of breast cancer is increasing age. **Zaid et al., (2016)** research has shown that breast cancer can strike at any age and becomes more prevalent with increasing age.

The majority of the sample were married, not employed congruent with **Mohamed & El-Sebae., (2013)** who stated in their study that the majority of the sample were housewives and married. Also, The present study mentioned that most of the studied patients were illiterate. This finding consistent with **Abd El-Razik, (2010)**, whose study revealed that the highest percentage of the breast cancer patients were illiterate regardless of the type of surgery. So more attention has to be paid in designing educational materials for breast cancer patients who are illiterate or less educated.

In this study the highest percentage of the studied patients were living in urban areas, it might be due to the more exposure to regional environmental air pollutants. This study finding is congruent with **Mohamed & El-Sebaee, (2013) & Pakseresht et al., (2009)** who stated that, large number of breast cancer patients were living in urban areas. These findings were supported by **Dey et al., (2011)** who concluded that the incidence rate of breast cancer was three to four times higher in urban areas than in rural areas across all age-groups.

Part II –Medical data

The present study found that the highest percentage of the studied patients were in second stage and this is because of seeking medical advice at late stage and a lot of time consumed to confirm diagnosis, this result is in line with **Yi et al., (2007)** who reported in their study findings that more than half of the studied group were diagnosed at the second stage. Also, **El-Shinawi et al., (2013)** added that in general, most of Egyptian patients diagnosed at an advanced stage .

Findings of this study revealed that the majority of the studied patients have family history of breast cancer. This result goes in line with **American Cancer Society, (2012)** that mentioned; breast cancer increases with an increasing risk factors including family history. Also, **El-Shinawi et al., (2013)** stated that almost half of women had a family member with breast cancer.

Regarding reason of attention to breast cancer, patients observed the presence of breast mass. This result is in agreement with a study by **Sandhu et al., (2010)** who emphasized that lump in the breast was a dominant symptom. **El-Shinawi et al., (2013)** stated that the majority of patients recognized a painless breast mass as a breast cancer symptom.

Part III - knowledge of studied patient

Regarding sources of knowledge about breast cancer, the present study revealed that more half of the studied patients gained their knowledge from social media. This result goes in agreement with **Montazeri et al., (2008)** who mentioned that most of the respondents' source of information about breast cancer was from electronic media (television and radio). **Syed., (2011)** reported that most of patients had gained the information from the electronic media. The present finding differed with **Huang & Penson., (2008)** who found that health-care professionals are still the main source of information used by cancer patients. As well as **Zaid et al., (2016)** who mentioned that the respondents mainly utilized information from their personal doctors, oncologists, family and friends and nutritionists, and found information from these sources very helpful.

Part IV- informational needs related to disease, examination, treatment, physical and psychosocial aspects

As regard to importance needs of information among the patients under study, the study findings showed that information needs about treatment was first, disease was second and examinations was third, this result goes in line with **Graydon et al., (1997)** who concluded that all breast cancer women wanted information about their disease, treatments and investigative tests. Also, **Nagler et al., (2010)** stated that patients most frequently reported seeking about treatment information, but they desired information about other topics too including their chances of survival or cure. **Bei et al., (2015)** mentioned that extent of the disease was the second most common item of information needs. **Kimiafar, et al., (2016)** stated that eighty-five percent of patients desired more information about their disease. **Valero-Aguilera et al., (2014)** results showed that women with breast cancer are more interested in information about the risks and benefits of the treatment in the long term. In addition **Zaid et al., (2016)** stated that the women gave more emphasis to three main types of information: treatment, management and self-care. **Polly et al., (2011)** stated that the priority of participants information needs was centered on aspects of disease and treatment rather than on sexual attractiveness. According to **Syed., (2011)** among all participants more than half respondents said that breast cancer screening is very important.

The study results represented a significant relation between education and total information needs, this goes in line with **Mohamed & El-Sebaee, (2013)** who found that educational level had a statistically significant relation with total information needs. This may be due to that educated patients have more awareness to their health conditions than non-educated and want to know more about their health status. Also, **Bei et al., (2015)** stated that patients with a higher educational level are more eager to know more about their treatment options and the associated advantages and disadvantages.

Conclusion

Newly diagnosed breast cancer women had high important informational needs regarding to disease, treatment, examination, physical and psychosocial domains. Patient knowledge regarding breast cancer were inadequate. It was found that educational level had a statistically significant relation with total informational needs. Also, it was found that occupation had a statistically significant relation with total informational needs. So the specialized designed nursing guidelines meeting the information needs of breast cancer patients are crucial for implementing

the quality of self care among such groups of patients.

Recommendations

Based on the findings of the present study the following recommendations are suggested

- 1-Establishment of specialized resource centers in different governorates of Egypt,rural and urban areas for meeting informational needs among women with newly diagnosed breast cancer.
- 2-Specific information on recurrence should be offered to all women with breast cancer.
- 3-Further study is recommended to evaluate the effect of implementing nursing guidelines on the quality of self care among women with breast cancer.

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