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INFORMATION NEEDS AMONG BREAST CANCER PATIENTS UNDERGOING SURGERY IN A TEACHING HOSPITAL

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ABSTRACT

Little is known about the information needs for women with breast cancer specifically in the information needs before and after surgery. The purpose of this study was to explore the information needs of breast cancer patients undergoing surgery.

In total 90 women with breast cancer were obtained which included 10 patients for pilot project study from Clinical Oncology Unit and Breast Clinic. The sample was the breast cancer patients who had undergone mastectomy with a time frame of one month and up to maximum of one year after surgery. A quantitative, descriptive and non experimental cross sectional design was used and a convenience sampling was chosen. The instrument in this study was a questionnaire which was adapted from Lithner & Zilling (1999) with their study on "Pre- and postoperative information needs". Women have great information needs for having mastectomy and is above 70% ranked important for all nine information subscales. There is difference in information needs of breast cancer patients in pre-operative and post-operative phases of surgery. There are significant associations between age, education level and household income group with information needs. The implication for nurses is providing appropriate information needs for breast cancer patients accordingly.

INTRODUCTION

Breast cancer is the most common cancer among women in most parts of the world. There is a marked geographic variation, with a higher incidence in developed countries compared to developing countries *(Hashim & Yip, 2004)*. In recent years, a step increase in incidence rates has been reported in Asia which included Malaysia. In 2006, there were total 3525 female breast cancer cases registered in National Cancer Registry and accounted for 16.5% of all cancer cases registered *(Omar, Mohd. Ali & Ibrahim Tamin, 2006)*.

Nurses and other health care professionals who provide care to breast cancer patients have to face the challenge in finding a way of providing information that is relevant and appropriate for patients who may benefit from knowing something about their illness and its treatment but may not wish to know everything about it at one time. This is particularly important in the period of before surgery or newly diagnosed because receiving a diagnosis of breast cancer is a crucial experience for most women. The patient have little or no time emotionally or psychologically to accept the diagnosis of a life-threatening illness before they are asked to consider treatment options and deal with the physical impact of the chosen treatment *(Galloway et al., 1997, cited in Lee, Francis, Walker & Lee, 2004)*.

Over the 16 years period from 1993 to 2008 which totally comprised 3689 cases of breast cancer patients in a teaching hospital, Klang Valley, there are about 251 cases of newly diagnosed patients in each year. According to the statistic from Surgical Department, there was total 292 patients diagnosed breast cancer in year 2008. With that, mastectomy surgery comprised 180 patients.

According to Simpson et al. (1991), service users may not be receiving either the right amount or types of information. Another study done by Girgis, Boyes, Sanson-Fisher & Burrows *(2000)*, reported that majority of women with breast cancer did not meet the information needs particularly in the information and psycho-social domains. Thus, it would be prudent to be more strategic and to examine the priority information needs over period of, before, during and after surgery to prevent overloading individuals with information that they may not be able to recall at a later date.

There is a lot of evidence from studies relating to the information needs of breast cancer patients that information is desired by this client group *(Gray et al., 1998; Graydon et al., 1997; Luker et al., 1996; Lee et al., 2004; Beaver et al., 2006; Gopal et al., 2005; McCaughan et al., 2000)*. From a review of this research, it was evident that women with breast cancer have distinct information needs throughout their breast cancer journey.

In addition, women have high information needs irrespective of the particular treatment they are receiving like surgery, chemotherapy and radiotherapy. It is apparent from the literature that suggested time could be better spent establishing the priority information needs of women with breast cancer at different points of time *(Luker et al., 1996)*.

GENERAL OBJECTIVE

The general objective of the present study was to explore the information needs among breast cancer patients undergoing surgery in one teaching hospital.

SPECIFIC OBJECTIVES

1) To identify the information needs among breast cancer patients undergoing surgery.
2) To determine the subscales of information needs among breast cancer patients undergoing surgery in the two different phases:
   - pre-operative
   - post-operative
3) To identify the sources obtained by the breast cancer patients undergoing surgery
4) To determine the association between the demographic profile variables and the subscales of information needs among breast cancer patients undergoing surgery.
5) To determine the association between the demographic profile variables and the overall information needs of breast cancer patients undergoing surgery.

METHODOLOGY

This was a quantitative, descriptive and non experimental cross sectional survey using a questionnaire to explore the information needs of breast cancer patients who had undergone surgery.

A convenience sampling method was used for this study. Total 90 respondents were recruited in this study which included the pilot study. The following criteria were used in order to get the correct type of participants:

- Breast cancer patients who had undergone mastectomy between one month to one year duration;

Table 1: Profile Characteristic of the Respondents (n=80)

Characteristic	f (%)
Age	53.3 (10.2)*
Age Group	
33 – 45	18 (22.5%)
46 – 58	34 (42.5%)
59 – 71	28 (35.0%)
Ethnicity	
Malay	11 (13.8%)
Chinese	55 (68.8%)
Indian	13 (16.2%)
Others (Bidayuh)	1 (1.2%)
Marital Status	
Single	2 (2.5%)
Married	76 (95.5%)
Separated/Divorced	–
Widowed	2 (2.5%)
Educational Level	
No formal education	5 (6.2%)
Primary education	11 (13.8%)
Lower secondary education (Form 3)	16 (20.0%)
Upper secondary education (Form 4–6)	17 (21.2%)
Vocational education	11 (13.8%)
University/College	18 (22.5%)
Others	2 (2.5%)
Monthly Household Income	
No income to RM1,000	15 (18.8%)
RM1,001 to RM3,500	30 (37.5%)
RM3,501 and above35 (43.8%)	
Surgery Duration	
1 to 6 months	49 (61.2%)
7 to 12 months	31 (38.8%)

**** Mean (SD)***
n=80

- No previous experience of having other cancer diseases;
- No previous experience of having other surgery as cancer treatment;
- Ability to read English, Malay or Mandarin language, or understand Cantonese or Hokkien language;
- Age 18 years or above;
- Women with breast cancer;
- Mentally and physically competent to participate in the study.

Ethical approval was obtained from the Research Ethical Committee before conducting the study. Participation was voluntary, with questionnaire completion implying consent. Confidentiality was maintained throughout the study, with anonymity being assured in analysis and reporting of findings.

The data was keyed in into computer system by using the Statistical Packages for the Social Sciences version 16. In order to examine the association significance of the demographic characteristic variables on information needs, statistical significant analysis of each variable was assessed by chi-square test. The statistical test was set at 5% of significance (p=0.05).

FINDINGS

The study sample consisted of 80 women recruited from Clinical Oncology Unit and Breast Clinic in a teaching hospital. Table 1 shows the Summary of Demographic Characteristic of the respondents:

Information Needs

Table 2: Information Needs of the Respondents by Items

No.	Items	Not Important *f* (%)	Important *f* (%)
	Information: Treatment and Complications		
1.	The cosmetic outcome of the surgery	16 (20.0%)	64 (80.0%)
2.	The length of surgery procedure	25 (31.2%)	55 (68.8%)
3.	Complications that can arise after surgery	10 (12.5%)	70 (87.5%)
4.	What are the symptoms of possible complications	8 (10.0%)	72 (90.0%)
5.	How the operation will be performed	16 (20.0%)	64 (80.0%)
6.	Any alternative treatments besides surgery.	17 (21.2%)	63 (78.8%)
.	**Information: Activities of living**		
1	Can I lift heavy things after surgery.	4 (5.0%)	76 (95.0%)
2.	How I shall move after surgery.	0 (0.0%)	80 (100.0%)
3.	How I can best prepare myself physically before surgery	4 (5.0%)	76 (95.0%)
4.	Activities I should avoid after surgery.	2 (2.5%)	78 (97.5%)
5.	Activities I should do to prevent complication.	3 (3.8%)	77 (96.2%)
6.	What kinds of food I can eat after surgery.	2 (2.5%)	78 (97.5%)
7.	When I can intimate relationship with my partner.	28 (35.0%)	52 (65.0%)
8.	When I can resume work.	47 (58.8%)	33 (41.2%)
	Information: Feelings related to condition		
1.	How I may feel just after surgery.	14 (17.5%)	66 (82.5%)
2.	How I may feel when I come home	12 (15.0%)	68 (85.0%)
3.	How I can best prepare myself mentally before surgery.	12 (15.0%)	68 (85.0%)
	Information: Wound care and the drain		
1.	When I can wet the wound.	0 (0.0%)	80 (100.0%)
2.	Whether the stitches need to be removed.	2 (2.5%)	78 (97.5%)
3.	How to care for the drainage bottle after surgery.	4 (5.0%)	76 (95.0%)

No.	Items	Not Important f (%)	Important f (%)
	Information: Pain treatment		
1.	How my pain will be treated after surgery.	3 (3.8%)	77 (96.2%)
2.	If I have pain at home, what can I do.	5 (6.2%)	75 (93.8%)
	Information: Hospital routines		
1.	How many days will I be at the hospital.	14 (17.5%)	66 (82.5%)
2.	The day schedule at my ward.	25 (31.2%)	55 (68.8%)
3.	What will happen on the first day of admission, including the admission procedure.	10 (12.5%)	70(87.5%)
	Information: Community and follow-up		
1.	Whom to address with questions after surgery.	18 (22.5%)	62 (77.5%)
2.	The next treatment plan after surgery.	2 (2.5%)	78 (97.5%)
3	The length of sick-leave.	45 (56.2%)	35 (43.8%)
4.	When is the appointment date for a check-up after surgery.	3 (3.8%)	77 (96.2%)
5.	Information about breast cancer survivor support group.	11 (13.8%)	69 (86.2%)
	Information: Bra and prosthesis		
1.	What I should wear after the surgery.	3 (3.8%)	77 (96.2%)
2.	When can I wear the bra again after surgery.	1 (2.2%)	79 (98.8%)
3.	Where can I get the breast prosthesis.	8 (10.0%)	72 (90.0%)
4.	How the breast prosthesis and bra look like.	7 (8.8%)	73 (91.2%)
	Information: Psychological coping		
1.	How I may react to mastectomy.	14 (17.5%)	66 (82.5%)
2.	How to psychologically prepare myself for the cosmetic outcome.	10 (12.5%)	70 (87.5%)

Table 3: Information Needs of Respondents by Each Subscale

No.	Information Subscales	Not Important f (%)	Important f (%)
1.	Treatment and Complications	9(11.2%)	71 (88.8%)
2.	Activities of living	3(3.8%)	77 (96.2%)
3.	Feelings related to condition	12(15.0%)	68 (85.0%)
4.	Wound care and the drain	1(1.2%)	79 (98.8%)
5.	Pain treatment	3(3.8%)	77 (96.2%)
6.	Hospital routines	17(21.2%)	63 (78.8%)
7.	Community and follow-up	11(13.8%)	69 (86.2%)
8.	Bra and prosthesis	7(8.8%)	73 (91.2%)
9.	Psychological coping	9(11.2%)	71 (88.8%)

n= 80

Table 2: Indicates the frequency and percentage of 36 items of information needs. Majority of the respondents are ranked important for each item of which it comprises 70% and above. There are only 5 items of information below 70% which includes:

- The length of surgery procedure (68.8%),
- When can I intimate relationship with my partner (65%),
- When can I resume work (41.2%),
- The day schedule at my ward (68.8%)and
- The length of sick-leave (43.8%).

Table 3: Majority (70.0% and above) of the respondents has rank that each group of information are important for them. In the top 3 information group, it comprised 98.8% of the respondents had felt that wound care and the drain domain were important for having breast cancer surgery followed with activities of living (96.2%) and pain treatment (96.2%) domain.

Different Phases of Information Needs

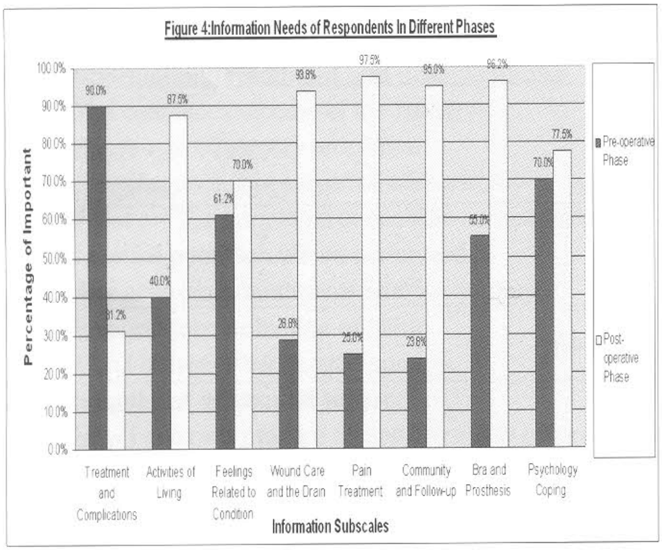

Figure 4: illustrate the comparison of the information needs of respondents in pre-operative and postoperative phases by each subscale.

Source of Information

Table 5: Sources of information of the respondents

Sources of information	Mean
Survivor support group members	3.4
Friends	3.3
Family members	3. 2
Doctors	3.1
Nurses	2.7
Information resources from Breast Cancer Resource Centre	2.7
Books on breast cancer	2.6
Internet	2.5
Women magazines	2.3
Newspaper	2.2
Television	1.8

Table 5: Indicates the most important source of the respondents is survivor support group members follow (mean = 3.4) with friends (mean = 3.3) and family members (mean = 3.2).

However, the healthcare worker who included doctors and nurses are ranked fourth and fifth respectively.

Cross Tabulation of Responses

Information needs were found to be influenced by several demographic profiles in this study. Age, education level and household income were all found to influence information need priority rankings. In this study, younger women ranked information regarding Treatment and Complication, Feelings related to Condition, Pain Treatment, Community and Follow-up, Bra and Prosthesis and Psychological Coping higher than older women.

Overall, the breast cancer patients with higher education level needed more information in this study. The higher education group has greater importance of information related to treatment and complication, feelings related to condition, hospital routines, community and follow-up and psychological coping.

The results of study shown different household income of the breast cancer patients have effect of the overall information needs. The higher household income group needs more information about Treatment and Complication, Feelings related to Condition, Hospital Routines, Community and Follow-up and Psychological Coping.

Cross Tabulation with Overall Information Needs

Table 6: Association between selected demographic profile and Overall Information Needs

Characteristic	Overall Information Needs		
	Disagree f (%)	Agree f (%)	P-value
Age			
33 – 45	0 (0.0%)	18 (100.0%)	0.001*
46 – 58	0 (0.0%)	34 (100.0%)	
59 – 71	9 (32.1%)	19 (67.9%)	
Education Level			
Form 3 and below	7 (21.9%)	25 (78.1%)	0.001*
Form 4 and above	2 (4.2%)	46 (95.8%)	
Household Income			
RM 0 – 1, 500	5 (33.3%)	10 (66.7%)	0.003*
RM1,5001 – 3,500	2 (6.7%)	28 (93.3%)	
RM3,501 & above	2 (5.7%)	33 (94.3%)	
Surgical Duration			
1 – 6 months	4(8.2%)	45 (91.8%)	1.000
7 – 12 months	3 (9.7%)	28 (90.3%)	

***Fisher's Exact Test**

Table 6 shows three profile characteristics that included age, education level and Household income group have significant association with group of information regarding Psychological coping ($p< 0.05$). There is no significant association between surgical duration and psychological coping with p-value 0.143.

DISCUSSION

In previous studied by Galloway & Graydon (1996), found information related to treatment, complication, and activities of living were identified as highly important. Similarly result here is information subscale regarding Activities of Living was ranked highly important in both studied. This information would help an individual formulate self care activities in the early recovery period at home.

The bottom 3 ranked of important subscales of information are 1) Hospital Routines (78.8%), 2) Feelings related to Condition (85.0%), and 3) Community and Follow-up (86.2%). Similarly results with Galloway & Graydon *(1996)*, reported less priority of information about what is available in the community and how to handle feelings about the illness. It can be explained because of the physical implications of cancer and surgery has an immediate impact on the individual; hence, information related to disease, treatment and physical aspect of care is of more importance than information of an interpersonal or community nature *(Derdiarian, 1986 cited in Galloway & Graydon, 1996)*.

In the pre-operative phase, only Treatment and Complications was ranked higher in importance when compare with post-operative phase. This subscale of information could help the breast cancer patients to understand more about the outline of mastectomy, complications of surgery, and symptoms of possible complications. In contrast with study by Litner & Zilling *(2000)*, the patients wanted to receive information about Treatment and Complication regardless before or after surgery *(Litner & Zilling, 2000)* for having cholecycstectomy.

According to Litner & Zilling *(2000)*, reported patients were more interested in receiving information about wound care on discharge than at admission. It is similar with this study that Wound Care and Drain were ranked as higher importance after the surgery. The breast cancer patients more preferred information such as self care activities, explore their feelings, where can they get the breast prosthesis and to whom to address with question after their breast surgery.

However, feelings related to Condition and Psychological Coping were ranked almost equally important in both phases of surgery. It is not surprising, in fact most of the women may develop emotional distress for having breast cancer and making a decision for mastectomy during the short period of times. Indeed, after mastectomy, 20–30% of patients develop persisting problems with body image and sexual difficulties *(Dixon, 2006)*.

Malaysian hospitals still facing shortage of surgeons and nurses who specialised in breast care to give health professional expertise in caring for breast cancer patients. Unlikely, breast care nurses in Australia are well developed and recognized as important source of verbal information for breast cancer patients *(Szwajcer, Hannan, Donoghue & Mitten-Lewis, 2004)*. Although Specialist breast care nurses are not generally a feature of the healthcare system in Malaysia, general nurse training does emphasize the key role as an educator and providing information *(Gopal et al., 2005)*. Most possible arguable that information given by general nurse in Malaysia could not meet the specialist information need by breast cancer patients.

Information needs were found to be influenced by several demographic profiles in this study. Similarly with the previous studied by Graydon et al. *(1997*), reported that younger women had a greater need for information. Another studied done by Jenkins, Fallowfield & Saul *(2001)*, stated that there was a significant association between age and the amount of information required by the cancer patient; although a large proportion of elderly patients wanted as much information as possible.

In the literature reviewed by Pinquart & Duberstein *(2004)*, stated age-differences in information needs vary by topic of information. Older women (50 years old and above) rated information about physical appearance and sexual attractiveness as less important as did younger women. It is similar with this study, information needs regarding Brassiere and Prosthesis and psychological coping also more important for younger breast cancer patients. It can be explain that age-associated increase in the decline of the importance of the sexual relationship in old age and indirectly less likely facing the distress for having mastectomy. Moreover, women with breast cancer in younger age can experience a great sense of isolation due to not only facing a life-threatening illness but also they are still planning their lives and futures which breast cancer can interfere with *(Grosser, 2003)*.

In this study, younger women were more concern in the Treatment and Complication information needs in the sense they need information related to how the operation will be performed, complication can arise after surgery, any alternative treatments besides surgery and many more. The result was also consistent with a previous studied by Jenkins et al. *(2001)*, reported that older patients were less interested than younger patients in detail information such as what all the possible treatments, what were the possible side effects of treatment and how the treatment works to treat the illness. Besides, in the studied by Meredith et al. *(1996)* shown that younger patients (15–64 years old) were more likely to want information about all possible treatment when compare with older (65–74 years old) cancer patients.

The younger women were more motivated seeking in overall information needs and six subscales of information except Activities of Living, Wound Care and the Drain and Hospital Routines. It can be explain these three subscales of information are essential for all the patients undergoing surgery regardless any age group as supported by Galloway et al. *(1996)*.

This study has a few limitations. The study was confined to one teaching hospital and the sample size was relatively small and convenient. Therefore, this result cannot be generalized to all breast cancer women in Malaysia. Besides, the research was using a cross sectional study due to the time constraint that might possibly affect the actual information needs in preoperative and post-operative phase of the breast cancer patients.

RECOMMENDATION AND CONCLUSION

Nurses are often on the frontline of the care continuum, thus it is imperative that nurses are the key persons to provide information to women having breast surgery. However, meeting the information needs of breast cancer patients presents a real challenge to nurses. In order to optimise the nurses' time with the patients and enhance the effectiveness of the education; nurses should plan their education session that divided different subscales of information into pre and post-operative phase. The findings from the study have implications for nursing practice in the way of information regarding Treatment and Complications should be given before the surgery.

Many nurses requested additional knowledge in cancer care and communication skills with patients in different stages of illness. As a result, the researcher fully recommended that specialized nurses extend their role in breast care in order to fulfil the patients "right-to-know" and to provide more holistic care to the breast cancer patients. Actually, health care system in Malaysia is almost 30 years far behind from the developed country like Australia in establishing breast care nurse at breast care service; and yet already evident that breast care nurse can provide support and information to breast cancer patients throughout their cancer journey *(Szwajcer et al., 2004)*.

Nursing education should emphasize the important of providing information for breast cancer patients during their teaching session. Assessment in the competency of giving information to patients in the clinical area should be added in the clinical assignment as well. According to Oermann & Gaberson (1998), stated that clinical learning activities provide real-life experiences and opportunities for transfer of knowledge to practical situations. Whilst, nurse educators need to develop strategies that assist student nurses to evaluate the information needs of each breast cancer patients and acknowledge each patient is "nonstandard".

Besides, nursing education can collaborate with nursing service to conduct the teaching program and training in breast care for nurses who are working in the surgical area especially to enhance their knowledge in breast cancer, treatment, how to manage psychosocial aspect and communication skills. On top of it, educational tools and programs should more focus on Wound Care and the Drain, Activities of Livings and Pain Treatment seen patients ranked highly importance from the study.

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