RESEARCH ARTICLE

Older Women Breast Cancer Survivors: Decision Making, Sources of Information and Wellness Activities in Malaysia

Nor Aini Mohamed*, Mazanah Muhamad

Abstract

The purpose of this study was to profile older breast cancer survivors in Malaysia. In a survey study, a custom made questionnaire was administered to 69 breast cancer patients and survivors between 60 and 84 years of age in Peninsular Malaysia. The main ethnic group recorded was Chinese, followed by Malay and Indian. The majority of women were married (87%) and had children (84.1%). Just over half (53.6%) had primary and secondary education, whereas 24.7% had higher education. Fifty five percent of the study participants made their own decision on treatment, 60.8% exercised at least 3 times in a week, and 56.6% sought information from specialists. Our study suggests that older breast cancer survivors are aware of the importance of exercise in their daily lives and make attempts to be cancer free (e.g. doing exercise, recreational activity and have good relationships with friends and family).

Keywords: Breast cancer - older women - information - wellness - Malaysia

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Introduction

Breast cancer causes the most cancer deaths each year (World Health Organization, 2012). Of the approximately 178,480 new cases of female breast cancer diagnosed annually in the United States, and almost one-half arise in women of 65 years of age or older (Jemal et al., 2008). In Japan, approximately 30% of the breast cancer cases occurred in women age 60 years or older (National Cancer Centre, 2009). In Australia, 4,499 cases occur for women age 65 years or older, and the most common cause of cancer related death (Australian Institute of Health and Welfare, 2012). In a study in Kazakhstan, the peak age incidence of breast and cervical cancer are set on 60-69 years (Igissinov, 2011).

According to Department of Statistics Malaysia (2010), Malaysia is comprised of three main ethnic groups; Malay (55%), Chinese (24%), Indian (7%), Bumiputera (11%) and others (4%). Breast cancer is the most common cancer among women from all ethnicities. It is also the most common cause of cancer death among women in Malaysia (National Cancer Registry, 2007). A few studies have been conducted in Malaysia regarding the characteristics of the breast cancer patients (Suthahar et al., 2009). This includes the pattern of breast cancer presentation at a major referral breast cancer hospital in Malaysia, University of Malaya Medical Centre (UMMC) over a 10-year period from 1995-2005 (Taib et al., 2007). One of 20 women in Malaysia will develop breast cancer in her lifetime. The cancer incidence differs by ethnic groups, for example as 1 in 16 Chinese and Indian women, and 1 in 28 Malays will develop breast cancer (Yip, 2008). In relation to the older breast cancer survivors, a study found that after the age of 50, incidence decreased in the Chinese and Malays but continued to rise within the Indian sub-population (Toh et al., 2008). Zainal (2006), reported that 803 (22.8%) breast cancer cases were diagnosed in women age 60 and older. The cases reported in the first cancer registry was lower, 827 cases (19%) were reported in 2002. In a retrospective cohort study done by Ibrahim et al. (2012), found that 24.4% of respondents were diagnosed at the age of 60 years and older.

Despite the increasing breast cancer incidence among older women, to date research has not been conducted on the older group of breast cancer patients and survivors in Malaysia. Once diagnosed with cancer, these breast cancer patients need information to make informed decisions regarding treatment. They also need to practice a healthy lifestyle to maintain their quality of life and survivorship. Thus, this study sought to profile the older breast cancer survivors and also address the following questions; 1) Who make decisions on treatment for them? 2) What is their source of information? and 3) What wellness activities they practiced? in Malaysian context.

Older breast cancer patients prefer to receive less information about their illness and treatment and assume a less active role in making treatment decisions. For example, a cross sectional survey of 222 breast cancer patients aged 55 years or older in Los Angeles County found that older breast cancer patients were more comfortable than younger patients with leaving decisions to the physician (Pinquart and Duberstein, 2004). The

*Cancer Resource and Education Center, Universiti Putra Malaysia, Selangor, Malaysia *For correspondence: noraini.ain@gmail.com*

reasons were that (1) patients did not know enough about breast cancer, (2) they believe that doctors were the experts, (3) they felt unqualified to make judgments about medical problems, and (4) patients may have difficulty in understanding physicians' terminology (Maly, 2004). Besides health professionals, family members also play an important role in assisting cancer patients make decisions on treatment, especially patients 65 years and older (Shelton et al., 2012). A review of literature on decision-making and information provision in patients with advanced cancer pointed out that those who took an active role were younger and had a higher education level (Gaston and Mitchell, 2005). Younger and more educated women were likely to prefer more active roles (Almyroudi et al., 2010).

Older breast cancer patients get information from a variety of sources (Wong et al., 2011). Recent research shows that older women with breast cancer expressed a preference for information direct from health professionals (Fenlon et al., 2012) and not prefer to use newspapers and narratives (Gaglio et al., 2012). Furthermore, a study of 302 breast cancer patients found that women age 75 years and older were most likely to obtain information from their breast cancer physicians, friends, family (Carlsson, 2000) or member of their healthcare team (Tomaka, 2006). However, according to Carstensen (1999), many older adults prefer to seek information from friends and family members. The reason cited was because they are more likely to discuss the emotional needs.

Social support refers to support received (informative, emotional, or instrumental) or the sources of support (such as family and friends) that enhance the recipient's self-esteem or offer stress-related interpersonal relief (Reynolds et al., 1994) and plays an important role in the health of the aging population. Asian people recognized spouse and children as their main sources of social support (Yoo, 2012), including emotional and practical support (Thewes et al., 2003). Additionally, social support is an important factor which may influence the general well-being of people living with chronic and life-threatening health conditions like breast cancer (Dumont and Provost, 1999).

In Malaysia, most older people live in an extended family structure with deeply rooted family ties and religion as a way of life. Social ties and religiosity have been shown to improve the psychological wellbeing of older people (Sazlina et al., 2012). A qualitative inquiry on 30 older women in the United States with breast cancer aged 67 to 90 also revealed that women were most likely to choose family members as their primary support person (Loerzel and Aroian, 2012).

Greater social exchange and emotional support after a cancer diagnosis may benefit the women's survival by enhancing their coping skills, providing additional support, and increasing opportunities for obtaining cancer-related information (Chou et al., 2012). It term of volunteering among older people, it helps to contribute to the general welfare of the communities and the society, to have an opportunity to enjoy emotional satisfaction and subjective wellbeing, and to express their views about various social issues and the future (Wei, 2012).

The main purpose of this study is to profile older breast cancer survivors in Malaysia. This study attempted to identify the socio demographic background, stage of diagnosis, type of treatment received, and years of survivorship of the older breast cancer survivors. This study also tried to discover sources of information on cancer, and identify wellness activities that are practiced by the older breast cancer survivors. The results will help healthcare professionals in designing and implementing suitable interventions to improve quality of life among older breast cancer survivors.

Materials and Methods

This report of older breast cancer survivors is part of larger study, Learning Behavior in Breast Cancer Context whose purpose is to identify learning pattern in making informed decision of women diagnose with breast cancer. This study involved 400 breast cancer survivors from four regions in Peninsular Malaysia. To be included in the study, patients had to: (1) be diagnosed with breast cancer, (2) have finished all recommended treatments, and (3) be 60 years of age and above. Elderly is defined as those who are 60 years old and above (National Policy of Elderly, 2008). Out of the 400 respondents, 69 respondents were between 60 and 84 years old. The mean age is 66 and the median is 65.

The data were collected through individual interviews using survey questionnaires by trained enumerators. The breast cancer survivors who agreed to participate signed the consent form before an interview. A survivor in the context of the study is defined as one who had completed cancer treatment regime after being diagnosed with breast cancer.The survey instrument was developed from various sources; a review of literature, data from focus group discussions on 26 informants, and pilot testing. The respondents were recruited from two sources: (1) those that were undergoing follow up at public or private hospitals or cancer centres; and (2) members of cancer support groups. The support group can be (1) registered, (2) informal, non-registered support groups operating from hospitals; and (3) informal, non-registered support groups in the community. The data were analyzed using descriptive statistics frequencies and percentages, using SPSS version 16.0.

Results

The first set of findings in Table 1 below presents the respondents' socio demographic profile which includes race, marital status, children, residential area, level of education, work status, and the age when diagnosed. The main ethnic group recorded was Chinese, followed by Malay and Indian, in that order. The majorities of women were married (87%) and has children (84.1%). Many (75.4%) live in urban areas, while 11.6% resides in urban fringe. The rest choose to stay in rural areas. Just over half (53.6%) have primary and secondary education, whereas 24.7% have higher education, and only 14.5% of the respondents never attended school. Most respondents were not employed, but 11.5% continued to work, or were

Table 1. Socio –demographic Background (n=69)

Details		N	%
Age	60-65	41	59.4
	66-71	15	21.7
	≥72	13	18.9
Race	Chinese	46	66.7
	Malay	15	21.7
	Indian	7	10.1
	Others	1	1.4
Marital Status	Married	60	87.0
	Never married	9	13.0
Children	Yes	58	84.1
	No	11	15.9
Residential Area	Urban	52	75.4
	Urban fringe	8	11.6
	Rural	9	13.0
Education Level	Never attend school	10	14.5
	MCE/SPM	21	30.4
	Primary Education	16	23.2
	STPM/Matriculation/Diploma	6	10.3
	Bachelor Degree	7	10.1
	Master Degree	2	2.9
	Phd Degree	1	1.4
Work Status	Work with salary	3	4.3
	Self employed	5	7.2
	Not employed	61	88.4
Age when diagnosed	25-34	1	1.4
	35-44	3	4.3
	45-54	11	16.0
	55-64	39	56.5
	65-74	11	16.0
	75-84	4	5.8

self employed. In terms of age when diagnosed, more than half (56.5%) were diagnosed between 55-64 years old, and 16.0% were diagnosed between the ages of 65-74 and 45-54 respectively.

Table 2 displays the stage of diagnosis, type of treatment received and survivorship. The majority (89.9%) were diagnosed early, stage 1 and 2. In terms of treatment received, half (50.7%) underwent mastectomy and almost half were treated with chemotherapy (40.6%) and radiotherapy (49.5%). In relation to survivorship, more than half (59.4%) had survived for less than 5 years while and 21.7% have survived between 6-10 years and the remaining 18.7% have survived over 10 years. The mean year of survivorship was 6.6 years.

Table 3 shows the parties involved in making final decisions on treatment for the older breast cancer survivors. More than half (55.1%) of the study participants made their own decision. Only 7.2% give full trust to the doctors to make decisions for them. The rest included spouses and family members as part of the decision making process.

Table 4 shows the wellness practices among the older breast cancer patients. To maintain their physical health, the majority (60.8%) do exercise at least 3 times in a week, 14.5% do recreational activities everyday. Most get enough sleep and rest. Majority (63.8%) control their body weight. Most of the older breast cancer survivors also take actions to avoid unhealthy environments.

In terms of social relationships, most have activities with family and friends. Majority (68.1%) respondents

Table 2. Diagnosis, Treatment and Survivorship (n=69)

Details		N	%
Stage diagnosed	1	34	49.3
	2	28	40.6
	3	5	7.2
	4	2	2.9
Type of treatment	Lumpectomy	20	29.0
	Mastectomy	35	50.7
	Chemotherapy	28	40.6
	Radiotherapy	34	49.3
Survivorship	<5	41	59.4
(Mean=6.6 years)	6-10	15	21.7
	11-15	5	7.2
	16-20	4	5.8
	21-25	3	4.3
	>26	1	1.4

Table 3. Final Decisions on Treatment

Decision maker	Frequency	%
Not stated	5	7.2
Myself	38	55.1
Doctor	5	7.2
Members of family	6	8.7
Myself & doctor	2	2.9
Myself & husband	4	5.8
Myself & family members	5	7.2
Myself, doctor & husband	2	2.9
Myself, doctor, & family members	1	1.4
Doctors & family members	1	1.4

Table 4. Wellness Activities Practice (n=69)

Details		N	%
Physical Activities			
	Do exercise at least 3 times per week	42	60.8
	Do recreations activity everyday	10	14.5
	Get enough rest	59	85.8
	Get enough sleep	51	73.9
	Control body weight	44	63.8
Environment Health			
	Avoid toxic material	59	85.8
	Avoid polluted environment	60	87.0
Social relationships			
	With family members	65	94.2
	With friends	65	94.2
	Join cancer support group	47	68.1
Mind and spirituality			
	Do activities that give satisfaction	62	89.9
	Do hobbies	60	87.0
	Do activities that give calm	63	81.3
	Do spiritual activity	57	82.6
Community	Involved in voluntary work	35	50.7

have joined cancer support groups. To maintain their emotional and spiritual stability, most engage in hobbies and activities that are spiritually satisfying and calming. Slightly more than half (50.7%) are involved in voluntary work.

Table 5 above displays sources of information on cancer used by the participants. Overall, they sought information from medical professionals, print media, electronic media, from other people and organizations. In the medical professionals group, 56.6% sought information from specialists, followed by general

Table 5. Source of Information on Cancer (n=69)

Details		N	%*
Medical Professional	Specialist	26	56.5
	General Practitioner	39	37.7
	Nurse	10	14.5
	Other doctor	2	2.9
Print Media	Newspaper	21	30.4
	Health book	21	30.4
	Magazine	18	26.1
	Brochure	10	14.5
	Journal	11	15.9
	Religious material	2	2.9
Electronic Media	Television	17	24.6
	Internet	11	15.9
	Radio	6	8.7
	Cassette	1	1.4
	CD	1	1.4
Individual	Friends	32	46.3
	Family members	25	36.2
	Cancer survivor	7	10.1
	Support group member	10	14.5
	Counselor	4	5.8
	Community	2	2.9
	Religious Leader	1	1.4
Organization	Hospital	13	18.8
	Cancer society	8	11.6
	Health society	9	13.0

*multiple responses

practitioners, nurses and other doctors. They also referred to newspapers and book on health (30.4%). About 30% preferred to seek information from television. With regard to other people, quite a high percentage sought information from friends (46.3%) and family members (36.2%). Only 14.5% respondents sought information on cancer from other support group members. The hospital is the major source of information among cancer related organizations (18.8%).

Discussion

The findings demonstrate that the majority of the older breast cancer survivors in Peninsular Malaysia are Chinese, married with children, and reside in urban areas. Their education ranged from basic education to higher education and only a small number percentage never attended school. The highest numbers of survivors were diagnosed between 55-64 years old and more than half did not have a family history with cancer. They tended to undergo a mastectomy, compared to a lumpectomy, and were diagnosed at an early stage. More than half of the older breast cancer survivors made the treatment decisions on their own. They have families and friends in their support system. As expected, most were not employed as they were over the official working age in Malaysia. The mean year of survivorship in older women with breast cancer is 6.6. Cancer patients with social support will have a longer survival time (Chou et al., 2012).

As noted earlier, the older women with breast cancer have strong social support from family members. The older women have longer survivorship can also be due to early discovery at stages 1 and 2, and they completed of all recommended treatment.

One of the interesting findings is regarding who has made the final decisions on treatment. Results from the study shows that older breast cancer patients made treatment decisions on their own. This finding is inconsistent with a previous study who found that older breast cancer patients were more comfortable to leave the treatment decisions to the physician or assume a less active role in making treatment decisions (Pinquart and Duberstein, 2004; Gaston and Mitchell, 2005; Almyroudi et al., 2010; Shelton et al., 2012).

In relation to survivorship, information seeking on cancer is one of the coping strategies adopted by older adults with chronic illnesses to adjust to their condition (Basford, 2003). Consistently, the findings from this study show that older women with breast cancer in Malaysia do seek information on breast cancer (Wong et al., 2011). The most preferred sources of information are medical professionals (Tomaka, 2006) and individuals such as family and friends (Carlsson, 2009; Fenlon et al., 2012). The respondents prefer to seek information from family and friends because both parties can also fill their emotional needs (Carstensen, 1999).

Besides being one of the most preferred sources of information, caregivers including family members and friends also give social support. Caregivers are typically family or friends of the person with cancer, including spouses, daughters, sons, siblings, parents, other family members and close friends. Our finding shows that most of the older breast cancer patients studied receives their social support from caregivers, consistent with (Loerzel and Aroian, 2012; Yoo, 2012).

In addition, this study examined the wellness and support activity practiced by the older breast cancer survivors. Despite their age, they maintain a healthy lifestyle by exercising regularly and doing recreational activities. In terms of support activity, older cancer patients also join cancer support groups to strengthen the social ties which significant in improving their general wellbeing (Sazlina et al., 2012). Our study suggests that older breast cancer survivors are aware of the importance of exercise in their daily lives to assist them in remaining cancer free (e.g exercising, recreational activity and having good relationships with family and friends).

In conclusion, older breast cancer survivors in Malaysia survived the cancer challenge longer. The majorities are diagnosed at an early stage, complete all treatment and practice a healthy lifestyle. In terms of the socio- demographic profile, one of the issues that need to be addressed is regarding the financial needs of this group. The cancer treatments cost is a burden to the elderly women as the cost of are often prohibitive. It is important to point out that financial management is really important when dealing with a chronic disease such as cancer.

The older breast cancer survivors do utilize print media as a source of information. Due to their educational level, this group needs cancer education materials that are easy to understand in lower literacy version (e.g low literacy version). In recent years, many cancer related NGO's, in collaboration with government agencies, successfully organized social and recreation activities for cancer survivors and public. Through these activities, people

learn about the importance of practicing a healthy lifestyle. One important issue that needs to be given priority is the type of support provided by the caregivers of these older breast cancer survivors. As a majority of the older women with breast cancer are married and have children, they have family members who take care and support them. Therefore, for the caregiver, the knowledge of how to deal with cancer patients is really important. The caregivers need to be educated, not just on how to deal with the patients, but also knowledge about cancer as a whole. Further research is needed to asses or identifies the level of knowledge among older breast cancer survivors' caregivers.

This study has several limitations. The sample size was small (n=69) to generalize the findings for overall older breast cancer patients in Peninsular Malaysia. But, this study provides a basic pattern of older breast cancer patients and can be use as a guideline for future research. Another limitation is that the older breast cancer patients surveyed in this study were recruited from only two sources where they can be assessed, the hospital and support groups. Most of them followed all recommended treatments from the doctors. The recruitment employed in the study excluded older breast cancer patients who were not present at the hospitals or support group meetings, live in the rural areas, and choose alternative treatment. The findings, especially socio demographic will be slightly differing.

In summary, the study of older breast cancer survivors provides clear view on their profile. As they are older, considerations need to be taken into account in terms of the disease management. Even when they are diagnosed with an early stage of the disease (stage 1 and stage 2), they still have to practice healthy lifestyles in order to prevent recurrence. Cancer awareness campaigns and educational programs need to tailor to meet the needs of these old women, the survivor and also to the caregivers. This is really important because family history is also one of the risks factors in breast cancer. Family members at high risks ought to preventive actions, such as undergoing breast self examinations and mammogram on a regular basis. Educated cancer caregivers can help patients make wise decisions, in all aspects of the disease management and etc. Finally, more research needs to be conducted to gain inclusive pictures regarding the older women who have suffered breast cancer to ensure they lead a quality and meaningful life.

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