

RESEARCH COMMUNICATION

Family Support in Cancer Survivorship

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Abstract

This paper raises issues about the role of family members in providing support for breast cancer survivors. Data were collected from 400 breast cancer survivors in Peninsular Malaysia through a custom-designed questionnaire fielded at hospitals and support group meetings. The data were analyzed using descriptive statistics. The analyses show that all family members could be supportive, especially in decision making and help with emotional issues. The spouse was the main support provider among the family members (others were children, parents, siblings and more distant relatives). The results also indicated that a significant percentage practiced collaborative decision-making. Breast cancer survivors needed their family members' support for information on survivorship strategies such as managing emotions, health, life style and dietary practice. The family members' supportive role may be linked to the Malaysian strong family relationship culture. For family members to contribute more adequately to cancer survivorship, it is suggested that appropriate educational intervention also be provided to them.

Keywords: Breast cancer - survivorship - social support - family

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Introduction

Cancer is a major health issue worldwide. Likewise in Malaysia as reported by Lim (2005), "this disease has become increasingly important as a public health concern with the development and progress that has been achieved in this country" (p. 37). According to the Malaysian National Cancer Registry report 2002, one in four Malaysians will get cancer in their life time (Lim et al., 2003). This means that out of the estimated 28,250,500 people in Malaysia, 7,062,625 are at risk of developing some sort of cancer during their lifetime (Wikipedia, 2011). In 2006, breast cancer was the most important cancer in Malaysia and also the most common cancer among women (Omar et al., 2006). "A Malaysian women's cumulative risk of getting breast cancer during her lifetime is 1 in 19 with the highest risk being in Chinese women (1 in 14)" (Parsa et al., 2008). Approximately, out of 100 women who are afflicted with cancer, 30 of them will be breast cancer patients (Lim et al., 2003). This data shows that breast cancer is a serious disease in Malaysian society.

Yip et al (2009) conducted a study on breast cancer in Malaysia and found that 81.7% of breast cancer patients were on stage 1, 72.4% on stage 2, 39.9% on stage 3 and 12.9% on stage 4. It would seem that most of the patients are in early stage (stage one or two) breast cancer, and their chance for recovery is high. Even though the number of deaths from breast cancer is slowly declining, the incidence is still high and therefore cancer survivors need continued support. In fact, breast cancer has an impact

upon not only the individual, but also upon the family members (Morse & Fife, 1998). Most patients or survivors suffering from breast cancer are worried not only about the effect of the disease on themselves but also being a burden to their family. The burden might have an impact on the economic of the family, quality of life issues and relationships with family members (Grunfeld et al., 2004). "Managing cancer-related sequel is increasingly important as individuals live longer with the burdens of cancer and its treatments" (Shelby, 2006.). Beside the responsibility of taking care and supporting cancer patients, family members also play a significant role in encouraging healthy behaviors (Bevan & Pecchioni, 2008).

In line with this idea, Kotkamp-Mothes et al (2005) stated that "relatives and family members were increasingly seen as a source of social support for patients with potential influence on coping, morbidity and mortality". Similarly, Hann and his colleagues (2002) reported that patients who receive adequate support from their family members have less anxiety and depression, better adaptation and are more efficient in coping with their illness. It seems that family members can promote patient autonomy, help them to cope with stressful events and enhance mental well-being in patients with breast cancer (Ommen et al., 2008). Although the role of family in supporting cancer patients is critical, limited research has been conducted in Malaysia on this issue. The current study is based on this pressing need and seeks to determine; 1) the profile of breast cancer survivors; 2) the kind and extent of family support received by breast

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cancer survivors; 3) and 3) the type of informational support given by family members.

Social support is one of the most important factors in the rehabilitation of cancer patients (Boehmer et al., 2005). It has an impact on psychological well being, health and coping behaviors in patients. Spiegel et al (1981) conducted a study to compare 34 breast cancer patients who had participated in a support group program to 24 patients not attending this program. Their findings indicated that patients who attended this support group program and perceived adequate social support, had less anxiety, confusion, depression, and helplessness. Similarly, Boehmer et al (2005) found that cancer patients who have positive perception of social support, have better psychological well-being, better social adjustment and higher self-esteem. In fact, "social support acts as an anti-stressor reducing the negative impact of a disease". This is supported by Dresner (1993 cited in Stevens & Duttlinger, 1998) who studied about breast cancer support group and found that breast cancer patients who had participated in more support-group meetings, had less distress and tended to realize their hopes for emotional support and medical information. It would seem that social support can diminish the harmful physical and psychological impact of disease by prompting endocrinological, cognitive, and behavioral adaptation (Stevens & Duttlinger, 1998).

According to Kotkamp-Mothes et al. (2005), one of the crucial sources of social support for patients are relatives and family members. Support that is received from family is an important factor in prediction better quality of life and adjustment to the disease in breast cancer patients (Julkunen et al., 2009). In fact, family members can directly or indirectly help patients. Direct help comprises of informational, emotional, spiritual and appraisal support (Eriksson et al., 2006). "Indirect support involves participation in the patients' care and the sense among relatives that the patient is receiving good care". According to Ommen et al (2008), informational support helps patients to get information, knowledge, and skill regarding their problems and emotional support consists of empathy, care, and concern. Furthermore, "spiritual support involves the degree to which a person experiences a connection to a higher power (i.e., God or other transcendent force) that is actively supporting, protecting, guiding, teaching, helping, and healing" (Mackenzie et al., 2000). Finally, "appraisal support involves the provision of constructive feedback, affirmation, and social comparison"(Ommen et al., 2008).

In a longitudinal study of social support and recovery after surgery for women with breast cancer, Neuling and Winefield (1988) found that cancer patients need a great amount of emotional support from their family members, but not informational support. "Emotional support can be seen as a response to the disease which aims to stabilize the patient within the family and to reduce the fear of loss" (Kotkamp-Mothes et al., 2005). Adequate support for the patient depends on the adaptability and cohesion of the family. In fact, family cohesion shows the availability of emotional support. This is supported by Friedman et al. (1988) who studied about perceptions of fifty-seven women with breast cancer regarding family

adaptability and cohesion. Their results indicated that high family cohesion was positively related to adjustment to the illness in breast cancer patients. On the other hand, some researchers have emphasized the importance of informational support given by the family or partner as a tool of adjustment (Mok et al., 2003; Eriksson et al., 2006; Adams et al., 2009). In line with this idea, Mallinger, et al. (2005) carried out a study on 182 breast cancer patients to examine the relationship between patient-centered care and satisfaction with information. They found that patients, who were satisfied with information, had better psychosocial outcomes, including less mood disturbance, fewer depressive symptoms, and lower levels of anxiety. So, they concluded that patient satisfaction with information is an important component of improving the quality of healthcare.

Regarding religion and spirituality, some researchers such as Tisdell (2003) differentiate the two. According to Tisdell (2005), "religion is as an organized community of faith that has specific rules of behavior, and spirituality is equated with the personal, subjective experience of something greater than oneself. It is about how people make meaning, an aware honoring of the sacred in our lives". On the other hand, Ahmad et al. (2010) stated that there is no distinction between religion and spirituality. In fact, "most people experience spirituality within an organized religious context, especially in those cultures where religion continues to play a dominant role in the formation of identity and the ultimate values of those cultures" (Ahmad et al., 2010). For example, "in an Islamic context, religion is the broader construct which encompasses a way of life. It covers not only rituals but also politics, and social and economic life". Therefore, spiritual beliefs can be considered as a powerful motivator in coping beyond the illness.

In some studies there is a suggestion that spirituality can significantly influence patient's emotional well-being and his/her quality of life (F Ahmad, et al.; Pandey et al., 2005). This is parallel to findings by Levine and Targ (2002) who found that spirituality accounted for 46% of the variance in functional well-being. Also, they reported that spirituality is related to better health habits, less anxiety, and less depression. In the same study, Gibson (2003) reported that there were significant positive relationships between sense of coherence (SOC is a state that serves to promote health and well-being) and spiritual perspective ($r = .768$) and hope and spiritual perspective ($r = .561$). It would seem that religious faith can be considered as a pillar of strength for breast cancer patients (Gotay, 1984) and this belief can have positive impact on illness prevention, recovery from surgery, mental illness, and coping with illness (Peterman et al., 2002). Therefore, it can be concluded that family members should support intrinsic religiosity and promote spiritual well-being in patients to cope with cancer (Fehring et al., 1997).

"One specific support provider that seems to be vitally important in outcomes with breast cancer is the spouse" (Pukay-Martin, 2009). In fact, spouse plays an important role in supporting his wife, particularly in coping with the emotional stress and management of breast cancer (Baider et al, 2003; Kadmon et al., 2004). According to Barker

and Lemle (1984 cited in Yusoff et al., 2010), husband can help his wife in 3 ways: “expressing sympathy, cheer and comfort, affection or reassurance; giving advice or problem solving; and passive listening” . Spouses who are more satisfied with their relationships are more understanding and supportive (Barker & Lemle, 1984). In fact, the close relationship between couples influences the well-being of patients (Yusoff, 2009). Rees et al. (1998) conducted focus group discussions in the United Kingdom to identify the information needs of spouses of women with breast cancer from thirty patients’ and nine spouses’ perspectives. They found that “women and their spouses have similar information needs and commonly engage in information disclosure” (p. 1249). In line with this idea, Rees and Bath (2003) stated that patients and their spouses need information regarding “the disease, its diagnosis, its prognosis, its treatments, including the side-effects of those treatments, the expected course of recovery and the prevention of recurrence”. Also they added that information needs of patients and their family members will change with time since diagnosis and with treatment – related events. It would seem that social support is of equal important for family members and for patients. Therefore, spouses and patients who have greater perceived support will have fewer adjustment problems and lower psychological distress (Baider, et al., 2003).

Caring and supporting those affected by cancer is a challenging task for all. An inquiry on eleven family members who were care givers to eleven cancer patients by Suzan et al. (2008) revealed that family members encounter various issues. The study concluded that resolving the challenges can reduce the stress and conflicts for all involved. It also could enhance support that the family members can provide to the survivors.

In general, the review indicated that family members are the most important and valuable source of support for breast cancer patients and they can provide the greatest proportion of care for patients (Chang et al., 2008). In fact, “no country can provide formal health and social services adequate to serve as a substitute for the family and informal care systems”. Therefore, it is essential to “take steps to maintain and sustain the family support system before it begins to disintegrate”.

Materials and Methods

This descriptive research investigated the perception of 400 breast cancer survivors at different hospitals and cancer support groups in Peninsular Malaysia. A breast cancer survivor is defined as one that is diagnosed with the cancer. The research employed both quantitative and qualitative methods to obtain the required data. The quantitative method was in the form of a survey. The qualitative approach utilized a focus group interview. This paper is a part of a larger project and focuses on the quantitative part of the study.

The instrument was developed from various sources: a review of literature, findings from focus group interview, and pilot testing. The development of the semi-structured focus group questions was initially guided by the “Health Belief Model” (HBM) (Breastcancer.org, 2009). The

refinement of the focus group interview guide was also based on feedback from four breast cancer survivors before the actual focus group interviews were carried out. In the focus group interviews, the interview guide was used to ensure consistency in responses among groups while allowing flexibility for the informants to share their perceptions and experiences during the discussion. A total of five focus groups were conducted with 36 breast cancer survivors from cancer support groups in four states representing the East, Central, North, and South Peninsular Malaysia: Kelantan, Selangor, Penang and Johore. Each focus group was facilitated by two trained moderators and ran for approximately two hours. All focus group discussions were audio-taped and transcribed verbatim by a research assistant. For completeness and accuracy of the transcripts, another research assistant listened to the tapes and reviewed the transcripts. Finally, the focus group moderators reviewed the edited transcripts. For each focus group, the responses to each question were grouped together and read for emerging themes (Merriam, 2009).

The findings from the focus group interview were used for the development of the questionnaire. A panel of expert further examined the content validity of the questionnaire. The instrument was revised according to their suggestion. The reliability of the instrument was administered to 30 patients and the Cronbach alpha coefficient of this questionnaire was 0.81. The finalized survey form was submitted and approved by the research university ethical committee. In this study convenience sampling was used. Researchers assessed respondents who were breast cancer survivors at two locations, (1) hospitals where they do or follow up their treatment, and, (2) support group where survivors attend meetings or participates in the support group activities. At the beginning of data collection session, trained enumerators met with the breast cancer survivors. The purpose of the study and its potential usefulness was explained to the participants. Those who wish to participate were reminded to answer the questions honestly. They were assured of their responses confidentiality. Further, the enumerators briefed them on how to fill the questionnaire. They signed consent to participate form before filling the questionnaire themselves. The enumerators checked the questionnaire for completeness immediately upon return. A total of 400 survivors participated in the study. All the completed survey forms were used in the analysis. In this study descriptive statistics (frequencies, means and percentage) were used to describe and summarize the properties of the mass of data collected from the respondents (Gay & Airasian, 2000). By convention, an α level of 0.05 was established a priori for determining statistical significance.

Results and Discussion

The sociodemographic analysis showed that the highest number of the breast cancer survivors were from the Chinese ethnic group (46.50%; n=186) followed by the Malay (44.75%; n=179), and the Indians (7.75%; n=31). This result is consistent with Omar et al.’s (2006) study. According to Yip et al.(2009) the difference rate between the Chinese and Malay could be due to risk

factors associated with cancer. “The Chinese are more likely to have fewer children, have their first child later, and also to breast feed for shorter periods compared to the Malay women” (Yip, Taib, & Mohamed, 2006, p. 370). In term of religion, less than half of the respondents (45.3%) were Moslem, followed by Buddhist (35%), Christian (12.75%), and Hindu (6%). The women’s mean age when they were diagnosed with cancer was 46.9 years. Yip et al. (2006) carried out a study about incidence of breast cancer from 1993 to 2004 at the University Malaya Medical Center and found that the commonest age at presentation was between 40 to 49 years. Moreover, they reported that the mean age at presentation in Malaysia and other developing countries is lower than that in developed countries, where the mean age is 60 years. Findings of this study showed that almost half of respondents had 3 to 4 children (41.3%) and majority (72.3%) of them had been survivors for less than five years. Most respondents came from urban area (64.75%) and the vicinities (25.25%). This may be due to the fact that data of this study was collected at hospitals and cancer support group meetings. Both hospitals and support groups were more accessible to survivors from urban area and vicinity rather than those from the rural. The women were moderately educated. Majority were unemployed (55.25%), fulltime housewives and had relatively minimal income (<RM5000/ year).

Majority survivors (59.5%) had first degree relative with cancer. Among the first degree relatives, in term of ranking, the highest was sibling (29.1%), followed by mother (18.44%) and father (11.73%). These results are consistent with Lynch and Eeles’s (2011) arguments that a positive family history is a risk factor for breast cancer. According to Breastcancer.org (2009) report, “women who had their first full-term pregnancy after age 30 and women who never had a full-term pregnancy are at higher risk for breast cancer than those who gave birth earlier in life”. However, the findings showed that very few women gave birth for the first time when they were above 30 years old. Most of the women (43.75%) breast fed for relatively shorter period (≤ 6 months). Based on the breast feeding length criteria, these women can be categorized into those of with higher risk to breast cancer (Yip, et al., 2006).

Support by family member

Respondents reported that their family members, comprised spouse, children, parents, sibling and relatives, supported them in their cancer journey in various ways. These include helping in making decisions, providing emotional support, motivating and inspiring, giving information, spiritual guidance and providing facilities (for example assisting with household needs or hiring

maid). According to Table 1, all family members were supportive, especially on helping with decision making during treatment, and giving emotional support. This may be due to the fact that there are very strong relationships between the family members in Malaysian society (Redhwan et al., 2009). According to Ahmad & Muhamad (2010) relationship is important in the lives of Malaysian breast cancer survivors. Vast majority of the women studied reported getting close to family members for social support when diagnosed with the cancer. In time of duress, for example during sickness, it is a natural practice for the closely knitted family members to come for support. The findings showed that among family member, spouse was the most important support providers for breast cancer survivors. This result is consistent with Kotkamp-Mothes et al. (2005), Neuling and Winefeld (1988), Pistrang and Barker (1995) and Yousoff’s (2009) findings. They asserted that spouse is the most important source of social support as well as emotional, practical and informal help.

In term of making treatment decisions, majority respondents (52.0%) agreed that spouse was the person who contributed most, 26.3% identified siblings, 25.0% said children, 16.0% said parents and 14.0% said relatives. The obtained result of this study is congruent with the findings of Gilbar and Gilbar (2009) who conducted a study to examine similarities and differences between 57 breast cancer patients and their husbands in terms of doctor-patient/ husband relationships and shared decision making. Their findings indicated that although the patient is the most important party in the decision-making process in terms of participating in the process and agreeing with the decision; for patients, the involvement of their husband in the decision-making process is highly important and equal to that of their doctor. Similarly, Adams et al. (2009) stated that family members, particularly spouse play an important role in decision-making and facilitating choices for the patient’s benefit.

Further, in response to this question “who made the final treatment decision” almost half respondents (47.5%) reported that they make their own final decisions about their treatments. Final decision may also be made by or delegated to doctors or to members of the family (13.3%); and in a joint decision with combinations between any of the following: patient, doctor, husband, and family members (31.3%). In a systematic review of the literature about patients’ preferences for involvement in cancer treatment decision making, Hubbard et al. (2008) stated that breast cancer patients use different decision-making approaches about their treatments such as “Active, where the patient themselves decides on which would be the most appropriate treatment option for themselves. Collaborative

Table 1. Types of Support by Family Member

Types of support	Spouse		Children		Parents		Siblings		Relatives	
	n	%	n	%	n	%	n	%	n	%
Making treatment decisions	208	52.0	100	25.0	64	16.0	105	26.3	56	14.0
Emotional support	161	40.3	75	18.8	40	10.0	78	19.5	36	9.0
Inspiration & motivation	23	5.8	17	4.3	11	2.8	16	4.0	12	3.0
Informational support	14	3.5	8	2.0	9	2.3	7	1.8	8	2.0
Spiritual support	7	1.8	0	0	3	0.8	2	0.5	0	0
Provide facilities	3	0.8	0	0	1	0.3	2	0.5	0	0

(sometimes described as shared), where the patient, the doctor and family members jointly decide on the most appropriate treatment option and passive, where the patient leaves the decision on the most appropriate treatment option to the doctor". Furthermore, they added that most patients prefer a collaborative role. This is supported by Adams et al. (2009) who pointed out that decisions about treatment and care are often not made by patient alone, but are socioculturally, situationally and interpersonally contingent, and made in the context of family. Result of this study indicated that most of the survivors preferred an active role in their treatment decision-making. However, a significant percentage preferred a collaborative role, followed by those who preferred a passive role. This result is consistent with Shariff et al's (2008) findings. They found that although patients play an important role "in making cancer treatment decisions themselves, these decisions are actually guided by their physicians' recommendations and discussion with them and family members".

Regarding the emotional support, 40.3% of respondents identified their spouse as the most common source of support, followed by siblings (19.5%), children (18.8%), parents (10.0%) and relatives (9.0%). Literature confirmed these findings that cancer patients need a great amount of emotional support from family members to cope with illness (Eriksson, et al., 2006; Friedman, et al., 1988; Kotkamp-Mothes, et al., 2005). Moreover, the spouse is the main source of emotional support for women with breast cancer (Sandgren, Mullens, Erickson, Romanek, & McCaul, 2004). In line with this idea, Kleiboer et al. (2006) found that patients who receive adequate emotional support on a day have higher end-of-day positive mode. Similarly, Peters-Golden (1982) stated that husbands who provided support and empathy, their wives reported better adjustment. On the other hand, husbands who were not able to provide support during the breast cancer experience, their wives had higher levels of distress. Therefore, it can be concluded that adequate support by the spouse that is characterized by empathy, care and concern, has a stronger impact on the patients' well being.

With regard to giving inspiration and motivation, 5.8% identified the spouse, 4.3% the children, 4.0% the siblings, 3.0% relatives and 2.8% parents. According to Gibson (2003), inspiration and motivation are prerequisite for effective coping. In fact, motivation to live and a return to a normal life has a significant impact on recovery and it can be considered as an efficient way to cope with the disease (Taleghani et al., 2006). In line with this idea, Henderson, Gore et al. (2003) stated that strong relationship between family members can stimulate a patient to conquer the disease and attempt to recover as soon as possible. It would seem that such families can motivate and inspire patients to have a positive attitude toward their illness, to envision a better future and to work toward actualizing that awareness (Herth, 1993).

As for the informational support subscale, 3.5% of respondents reported that their spouse provided assistance with knowledge and information regarding their problems, 2.3% identifying parents, 2.0% children and relatives respectively, and 1.8% siblings. In response

to this question "why do you seek information from your family members?" about 26.0% of respondents indicated that they needed their family members support to reduce anxiety, 18.0% respectively needed their support to know more about their problem, and to find other way to deal with their cancer issue. Study results are consistent with Rees et al's (2003) findings that breast cancer patients seek information to relieve anxiety, to improve psychological wellbeing and to make informed treatment decisions.

According to Ahmad et al. (2010), "Malay women patients tend to turn to spirituality as a means of coping with the illness" (p.1). Many studies have indicated that religious aspects have a significant effect on physical and psychological well-being, and quality of life (Gall et al., 2005; Sawatzky, Ratner, & Chiu, 2005; Taleghani, et al., 2006). In fact, "patients searching for meaning in their difficult circumstances may find answers from their religious traditions, religious leaders, or treatment programs that draw upon religious belief or spiritual principles to motivate and inspire recovery" (Blass, 2007, p. 29). Although patients tend spiritually to deal with their challenging situation, findings of this study showed that survivors taking part in the study received less spiritual support from their family members. For example, only 1.8% reported getting spiritual support from spouse, 0.8% from parents, and 0.5% from siblings. In a country like Malaysia which comprised of different ethnic groups such as Malay, Chinese and Indian, people have different cultural beliefs and use different religious strategies to accept their situation and cope with their illness. According to Junda (2004), "family members can help patients maintain religious practices and encourage patients to participate in some health promoting rituals" (Junda, 2004). Therefore, interventions should be designed for specific needs of supportive care providers of different ethnicities in order to understand the importance of religious strategies of coping with the illness through worship and praying and try to fulfill this spiritual need (Taleghani, et al., 2006).

As can be seen from Table 2, breast cancer survivors could get information about cancer and treatment options, for example: chemotherapy, radiotherapy, treatment side effects, health management and etc from two sources; Interpersonal (medical professional and family members) and media (print media and electronic media). Findings of this study indicated that breast cancer survivors

Table 2. Information Content and Source (%)

Content	Medical Staff	Print Media	Electronic Media	Family Members
Managing emotion	28.5	17.0	17.3	22.5
Health management	41.3	28.0	24.5	18.5
Healthy lifestyle	31.0	25.8	20.5	18.3
Dietary practice	35.3	27.0	20.5	18.0
Treatment side effects	40.3	20.8	16.5	13.8
Chemotherapy	42.0	19.8	16.0	13.5
Treatment facilities	36.5	20.3	15.5	12.8
Spiritual guidance	24.3	13.8	12.5	12.8
Radiotherapy	40.5	20.0	15.3	12.5
Complementary treatment	26.7	15.0	12.5	11.3
Self breast examination	21.3	14.8	13.0	10.8

needed their family members' support for information on managing emotions (22.5%), health management (18.5%), healthy life style (18.3%) and dietary practice (18.0%). Shariff et al. (2008) stated that family members are a primary source of information for breast cancer survivors. "Women with breast cancer may prefer these sources of information because they find them more trustworthy than other sources" (Freimuth et al., 1989; cited in Rees, et al., 2003).

The respondents reported that their main source of information is medical professional. This result confirms Beaver and Witham's (2007) study that "health professionals are the forefront in providing information for both patients and their informal carers" (p.18). On the other hand, Cotton and Gupta (2004) stated that patients who rely on their doctor as only main source of information have less power in their health care, and the doctor-patient relationship is inherently unequal. It is interesting to note that although physician is a main source of information on where come to specific information on managing emotion, the survivors interviewed relies to family members almost as much as to physician. This is supported by Loh et al. (2007) who found that husband and family are the main source of support for breast cancer survivors in managing their emotions.

According to Beaver and Witham (2007), "access to health professionals is an important issue for patients" (p. 23). Medical professionals usually have limited time to address all their patients' needs during a visit. Hence, as evidenced from this study print media such as newspaper, book, magazine, and brochure can be utilized by survivors for information input. Jones's (2004) findings show that "print media are important sources of health information for many women and probably influence their perceptions of susceptibility and appropriate health-protective behaviors". However, this study finding indicated that the number of women who used these sources to get information about cancer and treatment options are relatively low. This may be due to the fact that Malaysians are reluctant readers (Pandian, 1997).

Some researchers such as Balmer (2005) believed that the electronic media and Internet are important information resources and can improve patients and their family's knowledge regarding their health problems. Ozanne and his colleague (2007) carried out a study about computerized decision aid for breast cancer prevention. Their findings showed that the level of patients' information competence that spent more time in using Internet was higher than patients who spent less time using this kind of services. In fact, Internet offers a number of attributes that can positively impact patients' autonomy, competence, and relatedness (Gustafson et al., 2008). Result of this study indicated that less percentage of women used these sources to get information about their disease and its treatment. Hence, health care providers should encourage breast cancer patients and their family to use a credentialed Web site that is comprehensive and regularly updated by objective and unbiased experts to assist them in coping with their disease (Fogel et al., 2002).

The present study adds to a growing body of research that describes the role of family members in providing

support for breast cancer survivors. Study results indicated that family members who were involved in the care of patients played a critical support role, especially on helping with decision making during treatment and giving emotional support. They could also provide assistance with information, knowledge and skill; give strength to the patients through inspiration and motivation, and provide supportive care for them. In this way, "they could act as a guaranty of stability in times of changes" (Kotkamp-Mothes et al., 2005).

Also, the study confirmed the importance of spouse in providing support for breast cancer survivors. According to Pukay-Martin et al. (2009), support from the spouse has an impact that cannot be compensated by other sources. Moreover, support that a patient receives from her husband depends on their relationship. Strong relationship between couple contributes positively to cancer survivorship and quality of life. However, when the relationship is distressed, the negative effects on patient's emotional and physical well-being can be far-reaching. Effective communication and positive relationship between couple can facilitate spouse support and both can be improved through couple-based interventions (Epstein et al., 2002).

In addition, study results showed that a significant percentage of survivors practiced collaborative role in their treatment decision-making. According to Hubbard et al. (2008), a collaborative decision making decreases patients' level of anxiety and improve satisfaction with the consultation. Since family members particularly husbands are crucial in giving advice and information for decision making, they ought to be included in the medical care team (Gilbar & Gilbar, 2009). Hubbard et al. (2008) stated that preferences in treatment decision making will change over time and influence by many factors. Therefore, "assessing preferences for involvement is not a onetime event but rather, a process that should be conducted throughout the duration of the patients' cancer journey" (Hubbard, et al., 2008).

It is a fact that "women diagnosed with breast cancer have distinct need for information throughout their breast cancer journeys" (Rees et al., 2003). This information can help them to make informed treatment decisions, to cope effectively with their personal and environmental issues, and to reduce their anxiety and distress. Despite some differences between the current study and prior research, the findings confirm that breast cancer survivors needed their family members' support for information, especially on managing emotions, health management, healthy life style and dietary practice. In this study, only small percent of participants reported getting informational support from family members. This may be due to their assumption that their family members may not have such information. According to Adams et al. (2009) if family and especially spouse want to help patient, they should have a wide range of information. "Lack of information not only deprives the family of an important coping resource, but also contributes to family stress, and may lead to family conflict and misguided patient support" (Ell, 1996). In fact, "information provide them with guidance for implementing care but more importantly, would reduce the stresses of care giving and the associated

burdens and feeling of inadequacy and helplessness arising from ambiguity” (Reed, 2000). Therefore, education and intervention programs should be provided for them based on their challenges. The continuous learning needs both to survivors and those who support them called for appropriate lifelong learning and outreach policies and programs to these cancer stakeholders.

This study had several limitations which may influence generalizability of the results. The current inquiry was part of a cross sectional research to profile breast cancer survivors and survivorship behavior. This paper reports findings on the survivors’ experiences getting support from family members in their cancer survivorship. Measures of family members’ needs and challenges in providing support for the breast cancer survivors were not included. Furthermore, method of sampling was a limitation. Due to limited access to breast cancer survivors, convenience sampling was used in this study. Although “this method is quick and easy to organize, there is no guarantee that the behaviors of these people represent behaviors of other groups (“Statistics and Probability”)”

Even with these limitations, this study suggests that breast cancer survivors need their family members support. Like in most other South East Asian countries with close extended kinship system, Malaysia can draw upon family members to support cancer survivors. This strategy would also contribute towards alleviating cancer burden in the developing country. In the fight against cancer, educational interventions should be provided to both survivors and their family members. These programs have beneficial effects on patient compliance, patient satisfaction, clinical outcomes, and quality of life (Molenaar et al., 2001). Structured education and support group-based programs play a major role in providing information about the illness, treatment and prognosis, as well as support (Todd et al, 2002). Othman et al (2002) conducted a study to evaluate a psycho-educational program (PeP) for cancer patients and their family in Malaysia. Their findings indicated that this PeP can significantly increase levels of knowledge among patients and their family. Furthermore, they suggested that different intervention programs should be developed based on the needs of patients and their family. Caffarella (2002) stated that culture is an important factor in planning program for adult. In fact, “culture affects every aspect of an individual’s life, including the way that health and illness are perceived by patients, their family, the doctor-patient relationship, and the health-care-seeking behavior” (Craigie et al., 2002). A thorough knowledge of these cultural factors will help organizations such as cancer support groups to design and implement culturally appropriate intervention programs for those affected by cancer.

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