

## The Stress of Caregiving: A Study of Family Caregivers of Breast Cancer Patients Receiving Oncologic Treatment at a Malaysian General Hospital

(Tekanan daripada Penjagaan: Satu Kajian Berkenaan Keluarga Penjaga bagi Pesakit Kanser Payudara yang Menerima Rawatan Onkologi di Hospital Besar di Malaysia)

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### ABSTRACT

*Many studies among caregivers of breast cancer patients have revealed that stress affects a significant proportion of this particular group. The situation among caregivers of breast cancer patients in Malaysia was however not known. This cross-sectional study aimed to determine the proportion of the family caregivers who experienced stress while caring for the breast cancer patients who were on oncologic treatment in Kuala Lumpur Hospital and factors which predict the stress among these caregivers. A total of 130 family caregiver-breast cancer patient dyads who were attending the Institute of Radiotherapy & Oncology, Kuala Lumpur Hospital during a 3-month study period were recruited by non-random sampling method. The caregivers' stress was measured using the stress domain of the depression, anxiety, stress scale (DASS-21) while other data obtained included the patients' and caregivers' socio demographic status, the patients' illness characteristics and the caregiving factors and the caregivers' perceived social support. About 1 in 4 (24.6%; n=32) caregivers of breast cancer patients were stressed. Duration of caregiving, sharing of caregiving burden, patients' age and patients' functionality were found to be significantly associated with stress (p value <0.05). All these factors, except for duration of caregiving, continue to be significant in the logistic regression analysis (p value <0.05). This study found that a high proportion of the family caregivers experienced stress. Identification of the predictors of stress among the caregivers may help in the prevention strategies of stress in this group of caregivers.*

*Keywords: Caregiver; oncology; stress*

### ABSTRAK

*Banyak kajian dalam kalangan penjaga pesakit kanser payudara menunjukkan bahawa sebahagian besar daripada mereka mengalami tekanan. Keadaan dalam kalangan penjaga pesakit kanser payudara di Malaysia bagaimanapun tidak diketahui. Kajian keratan rentas ini bertujuan untuk menentukan perkadaran penjaga yang terdiri daripada ahli keluarga pesakit yang mengalami tekanan ketika menjaga pesakit kanser payudara yang menjalani rawatan onkologi di Hospital Kuala Lumpur dan faktor-faktor yang meramalkan tekanan dalam kalangan penjaga. Seramai 130 pasangan pesakit kanser payudara dan ahli keluarga/penjaga pesakit yang menjalani rawatan di Institut Radioterapi Onkologi, Hospital Kuala Lumpur semasa tempoh kajian selama 3 bulan menyertai kajian ini melalui kaedah persampelan tidak rawak. Ukuran tekanan dibuat menggunakan domain tekanan bagi kemurungan, kerisauan, skala tekanan (DASS-21) manakala data lain turut diperolehi termasuklah sosio-demografi, ciri-ciri penyakit, faktor penjagaan pesakit dan persepsi sokongan sosial. Lebih kurang 1 dalam 4 (24.6%; n=32) ahli keluarga/penjaga pesakit kanser payudara mengalami tekanan. Tempoh penjagaan, perkongsian tanggungan penjagaan, umur pesakit dan keupayaan fungsi pesakit didapati berhubung kait secara signifikan dengan tekanan ahli keluarga/penjaga (p value <0.05). Semua faktor tersebut, kecuali tempoh penjagaan, kekal signifikan selepas analisis regresi logistik dilakukan (p <0.05). Kajian ini mendapati kadar peratus ahli/keluarga yang mengalami tekanan adalah tinggi. Mengenal pasti faktor-faktor yang mempengaruhi tekanan tersebut boleh membantu dalam merangka strategi bagi mencegah tekanan bagi golongan penjaga pesakit.*

*Kata kunci: Onkologi; penjaga; tekanan*

### INTRODUCTION

Breast cancer is the most common cancer in Malaysia, followed by colorectal, lung, cervix and nasopharynx (Zainal et al. 2006). Generally, about 1 in 20 women in Malaysia is affected by breast cancer (Lim et al. 2008). It was reported that almost 50% of the patients with breast

cancer presented at Kuala Lumpur Hospital were at the later stage of the illness (stage 3 and 4) (Abdullah & Yip 2003).

The diagnosis of breast cancer brings many implications in all aspects of the patient's life which will invariably lead to impairment in physical and psychosocial functioning

of the patient. In most of the cases, family members are the people who will be taking up the role of caring for the patient. Northouse (1995) found that the stage of illness when patients are undergoing treatment is the most stressful for caregivers. During the period of active treatment, the family has to carry out numerous caregiving tasks, such as managing the symptoms of the illness, administering medications, dealing with the side effects of treatment, transporting the patient to hospital appointments, assisting with daily tasks, including activities of daily living (ADL) and household tasks and providing emotional support for the patient (Bakas et al. 2001; Carey et al. 1991). Formica et al. (2008) found that there was impairment to caregivers' quality of life even in the early phase of cancer disease. The most debilitating changes in quality of life that were reported were occurrence of new psychosomatic symptoms and anxiety (Formica et al. 2008). In a study of family caregivers of lung cancer patients, Bakas et al. (2001) found that providing emotional support and monitoring illness symptoms are the most difficult and time-consuming tasks. As the caregiving tasks become more burdensome, the caregivers are at a greater risk to experience stress.

Findings from studies have shown that care-giving is a significant risk factor for morbidities and subsequent mortality. Schulz and Beach (1999) in a cohort study of 392 caregivers found that individuals who reported mental and emotional strain associated with care-giving had a 63% higher mortality risk than the non-caregiver controls. There is a greatly increased risk of dying for spousal caregivers above 65 years old who are experiencing ongoing emotional stress due to caregiving compared with those in the same age group who are not spousal caregivers (Barry 2010). Adult children who are caregivers, experience additional stress as they have other responsibilities to attend to such as caring for young children, managing their own household as well as careers and attempting to maintain an active social life (Barry 2010). With regards to cancer, several studies have shown that the patients and their caregivers reported higher level of psychological distress as compared with the general population (Covinsky et al. 1994; Nijboer et al. 1998).

Studies conducted on the caregivers of cancer patients have identified several factors that are associated with the caregivers' psychological distress as a result of caregiving. A review conducted by Nijboer et al. (1998) on studies of cancer caregivers found that caregivers' sex, age, relationship to the patient, income and social support are consistent predictors of negative psychological outcomes for the caregivers. This review found that caregivers who are female, young, spouse of the patient, from a lower socio-economic group and have poor social support report higher level of psychological distress. These findings have been reaffirmed in a study by Gaugler et al. (2005) whereby caregivers who are female and younger reported more symptoms of psychological distress such as exhaustion, fatigue and feeling trapped in care responsibilities. A more recent review by Rivera (2009) reported that other factors have also been found to be contributing

to caregiver depression, such as the burden of care, the caregiver's medical illness, ethnicity of the caregiver and the caregiver's level of mastery in providing care for the patient.

Patient factors also play a part in predicting caregiver distress. The association of cancer severity with caregiver's emotional distress has been demonstrated by Northouse et al. (1998) whereby couples of malignant breast cancer patients reported higher levels of emotional distress than couples of patients with benign cancer. Awadalla et al. (2007) in their study among female patients with breast or gynaecological cancer found that the caregivers are vulnerable and in need for support if the patient is recently diagnosed. Patient's treatment is another important factor that has been found to be significantly associated with caregiver distress. Gaugler et al. (2005) found that shorter duration of treatment predicts higher caregiver distress. This was explained as being due to the type of treatment which consists usually of chemotherapy that bears a lot of side effects. In terms of the patient's demographic characteristics, Awadalla et al. (2007) reported that patients who are less educated, single and not formally employed posed a risk for low quality of life in their caregivers.

Once the caregivers' physical and mental well-being are affected, the management of the cancer patients they are caring for would be compromised. This has been shown by several studies that the patients' quality of life, including the physical and psychological aspects, is affected when their caregiver reported emotional stress (Mellon et al. 2006; Northouse et al. 2002; Rabin et al. 2009). Therefore, there is a need for psychological problems of caregivers, like stress, to be recognized in order to minimize the detrimental effects on both the caregivers and the patient(s) they are caring for. Unfortunately, there has been inadequate effort in detecting distress among the caregivers as well as lack of support for them.

The Institute of Radiotherapy and Oncology, Kuala Lumpur Hospital is the major centre for oncologic treatment in Malaysia where breast cancer patients are referred to from all over the country for treatment. The patients who come here hail from various socioeconomic backgrounds. To the authors' best knowledge, no study has been done exclusively on caregivers of breast cancer patients undergoing treatment in this centre. The aim of this study was to determine the proportion of stress among the caregivers of breast cancer patients receiving oncologic treatment at Kuala Lumpur Hospital who participated in the study and to determine the predictors of stress among the caregivers.

## MATERIALS AND METHODS

This cross-sectional, non-randomized study was conducted at the Institute of Radiotherapy and Oncology at Kuala Lumpur Hospital, which is the major centre for oncologic treatment in Malaysia. Breast cancer patients represented the majority of all the cases admitted, comprising 1144 admissions in 2008. These statistics did not take

into account repeated admissions, thus the number of admissions shown did not represent the total number of patients. As for the outpatient clinic, breast cancer patients comprised almost 40% of the total number of the clinic attendees. Data for this study was collected from September to November 2010.

This study has included the caregivers of breast cancer patients that were admitted into the main wards, caregivers of patients who were receiving treatment at the day-care wards, as well as caregivers of patients that came to the outpatient clinic for regular follow-ups during the data collection period. Inclusion criteria were: the patient consented to participate in this study; caregivers identified by breast cancer patients as their primary caregiver; the caregiver is a family member of the patient; the caregiver was able to understand and converse in English or Bahasa Melayu sufficiently and the caregiver was able to give informed consent. As for the exclusion criteria, they were: caregivers of patients who did not want to participate in this study; caregivers who were not proficient in English or Bahasa Melayu; caregivers who are not family members of the patients and caregivers who are less than 18 years old because of the relative infrequency of children and adolescents in primary care-giving roles.

A total of 173 breast cancer patients accepted the invitation to participate in this study and were approached, out of which 130 fulfilled the study criteria. All the 130 respondents, both patients and their caregivers, completed the socio demographic questionnaires. Patients' socio demographic information were age, sex, ethnicity, level of education, occupation, income and marital status whereas for the caregivers, the additional socio demographic information obtained were relationship with patient and presence of medical illness. Patients and their caregivers also completed questionnaires on the patient's illness characteristics which comprised information such as duration and stage of illness, type and duration of treatment and functional scores using the eastern cooperative oncology group (ECOG) performance status (Oken et al. 1982) scoring (ranging from Grade 0 for 'fully active' to Grade 5 for 'dead'), as well as questionnaires on care-giving factors, looking at information such as duration of care-giving, number of other dependents, proximity to the hospital, shared care-giving and perceived social support (assessed using the 12-item multi-dimensional scale of perceived social support (MSPSS)). The MSPSS has been translated into Bahasa Malaysia and validated by Ng et al. (2010). The caregivers completed the depression anxiety stress scale-21 (DASS-21) (Lovibond & Lovibond 1995) in order to measure for stress. DASS-21 has been translated into Bahasa Malaysia and this version has been validated (Ramli et al. 2007). The ratings for stress in DASS-21 range from 'normal' (0 – 14) to 'extremely severe' (> 34).

All breast cancer patients who came for treatment during the recruitment period were invited to participate in the study. Those who were interested were given information sheets about the study. Once the patients agreed to participate and identified their primary caregiver,

consents were obtained from both the patient and their caregiver; followed by the interview of the patient and their caregivers. For most of the patients, their socio demographic data and illness characteristics questionnaires were filled by the researcher so as not to inconvenience the patients. Besides face-to-face interview, the patients' case notes were also referred to for information on the illness. Privacy was ensured as much as possible when interviewing patients and their caregivers.

Data were analyzed using the SPSS (Statistical Package for Social Sciences, version 18). Bivariate analysis using Chi-square test with Yates' correction was carried out for the categorical data while continuous data were analyzed using parametric test (t-test) for the normally distributed data or non-parametric test (Mann-Whitney U test) for data that were not normally distributed, to see association of each variable with the outcomes. Correlation and regression analysis were used to determine the significant factors that predicted stress, after controlling for the confounding effects.

This study was approved by the Research Committee, Department of Psychiatry, Universiti Kebangsaan Malaysia Medical Centre (UKMMC). Permission to carry out the study at Kuala Lumpur Hospital was obtained from Ministry of Health (MOH) Medical Research and Ethics Committee (MREC).

## RESULTS

A total of 173 breast cancer patients consented to participate in this study. However, 43 subjects (24.9%) were excluded in this study due to the following reasons: caregivers were not present ( $n=19$ ); caregivers were not the primary caregiver ( $n=6$ ); caregivers were not interested to participate ( $n=12$ ); caregivers were unable to understand English or Bahasa Malaysia ( $n=5$ ) and caregiver was not a family member ( $n=1$ ). Finally, 130 breast cancer patients and their caregivers participated in this study. All the patients and their caregivers completed the socio demographic questionnaires, questionnaires on the patient's illness characteristics as well as questionnaires on care-giving factors. The caregivers completed the DASS-21.

### CHARACTERISTICS OF THE PATIENTS AND THEIR CAREGIVERS SOCIO DEMOGRAPHIC, THE PATIENTS' ILLNESS FACTORS, THE CAREGIVERS' BURDEN OF CARE AND THEIR PERCEIVED SOCIAL SUPPORT

The mean age of the breast cancer patients group was  $52.5 \pm 10.8$  while the caregivers' group was  $42.8 \pm 14.5$  years. Almost all but one of the breast cancer patients were females. Majority of the patients (87.7%) were married compared with 65% ( $n=85$ ) in the caregivers' group whom were married while 34.6% of the caregivers were unmarried, divorced or widowed. Almost half of the caregivers ( $n=61$ , 46.9%) were spouses of the patients, 39.2% ( $n=51$ ) were the patients' children and 13.1% were the patients' siblings. One of the caregivers interviewed was a parent to the patient.

Malays made up the major ethnic group of the patients in this study ( $n=94$ , 72.3%), almost 21% were Chinese and the rest were Indians; the same distribution was found in the caregivers' group. It was found that almost 90% of the breast cancer patients were of non-tertiary educational background, with 7.7% ( $n=10$ ) not having received any formal education at all and only 13.1% ( $n=17$ ) received tertiary education. 73.8% of the patients were unemployed and 65.4% ( $n=85$ ) had no income.

In contrast, 29.2% ( $n=38$ ) of the caregivers received tertiary education, although majority of the caregivers did not get higher level education ( $n=92$ , 70.8%). Majority of the caregivers were employed ( $n=79$ , 60.8%). However, 61.5% ( $n=80$ ) of them had no income or received income of less than RM2000 per month.

Almost 56% of the breast cancer patients in this study were in Stage 3 and 4 of their illness while 33.1% ( $n=43$ ) of the patients were in Stage 2. 56.1% ( $n=53$ ) of the patients received active treatment whereby 31.5% ( $n=41$ ) received chemotherapy, 14.6% ( $n=19$ ) received radiotherapy, 10.8% ( $n=14$ ) received palliative care while 43.1% ( $n=56$ ) of the patients were receiving outpatient treatment during the study period. The illness duration ranged from 1 month to 216 months, with the mean duration of  $37.4 \pm 39.7$  and the median was 17 months. 24.6% ( $n=32$ ) of the patients were receiving daily treatment, 31.5% ( $n=41$ ) received treatment 3-weekly, 16.2% ( $n=21$ ) received treatment at 2 to 3 monthly interval, 6.9% ( $n=9$ ) received 4-monthly outpatient treatment and 20.8% ( $n=27$ ) of the patients received outpatient treatment every 6 to 12 months.

The functional status of the breast cancer patients in this study was an interesting observation. It was found that despite the high percentage of the patients on active treatment, 59.3% ( $n=77$ ) of them did not have much limitations in their functioning (ECOG performance score of 0 to 1). In the caregivers' group, majority of the caregivers did not have any medical illness while only 33.1% ( $n=43$ ) had some medical illness.

In terms of burden of care, two-thirds of the caregivers ( $n=85$ , 65.4%) provided care of more than 20 h a week to the patient while the rest provided care of less than 20 h a week. 61.5% ( $n=80$ ) have other dependents to care for and 38.5% ( $n=50$ ) cared for the patient only. 50% ( $n=65$ ) of the caregivers lived outside of the Klang Valley area and the other half lived within the area. Majority of the caregivers ( $n=90$ , 69.2%) shared their caregiving tasks with others.

For the caregivers' perceived social support, the range of score for the domain of 'significant other' was from 4 to 28 with the mean score of  $22.7 \pm 5$ . The score for the domain 'family' ranged from 6 to 28 with mean score of  $22.3 \pm 4.6$ . The domain of 'friends' had a score range from 4 to 28 with mean score of  $20.4 \pm 4.8$ .

#### ASSOCIATION BETWEEN THE CAREGIVERS' STRESS AND THE PATIENTS' SOCIO DEMOGRAPHIC AND ILLNESS CHARACTERISTICS

In this study, 32 caregivers, that is, 24.62% scored positively for stress. Bivariate analysis showed that the

age of the patient and the patient's functionality are factors that were significantly associated with stress among the caregivers. Caregivers of older patients were less likely to be stressed (OR=0.945, CI=0.901-0.991) while caregivers of patients with higher ECOG score, meaning low level of mobility and functioning, were more likely to develop stress (OR=3.79, CI=1.37-10.48). Table 1 summarizes the results.

#### ASSOCIATION BETWEEN THE CAREGIVERS' STRESS AND THE CAREGIVER'S SOCIO DEMOGRAPHIC CHARACTERISTICS, BURDEN OF CARE AND RESOURCES

Bivariate analysis was also carried out to see the associations between the caregivers' stress and the caregivers' socio demographic characteristics, caregiving factors and perceived social support. Two factors were found to be significant: duration of caregiving ( $p$  value < 0.05, OR=3.724, CI=1.32-10.492) and shared burden of caregiving ( $p$  value < 0.05, OR=3.083, CI=1.342-7.085).

In other words, caregivers who looked after the patient for more than 20 h a week and caregivers who did not share their caregiving burden were more likely to develop stress. Table 2 shows the results in detail.

#### FACTORS THAT PREDICT STRESS AMONG THE CAREGIVERS

Logistic regression was performed on the data to adjust for confounding factors and collinearities in order to determine the significant predictive factors for the outcomes of this study. The analysis found 3 factors which significantly predict the caregivers' stress in this study: patient's age (OR=0.945, CI=0.901 - 0.991); patient's functional status (OR=6.714, CI=1.585 - 28.448) and sharing of caregiving burden (OR=2.810, CI=1.022 - 7.72). Table 3 summarizes the findings.

#### DISCUSSION

It was found in this study that 1 in 4 caregivers of breast cancer patients were stressed. Generally, caregivers have higher levels of stress than non-caregivers (Pinquart & Sorensen 2003). Approximately 16% of caregivers feel emotionally strained and 26% acknowledge that taking care of the patient is hard on them emotionally (Center on Aging Society 2005). Care-giving can also cause constant worry (Center on Aging Society 2005). In addition, caregivers feel less in control of their lives than non-caregivers (Marks et al. 2002; Pinquart & Sorensen 2003), which can be related to stress. As a result of feeling stressed too, many feel they cannot handle all their care-giving responsibilities (Center on Aging Society 2005).

Caregivers looking after breast cancer patients with limited functionality were 6.7 times more likely to experience stress. Weitzner et al. (2000) had identified functional dependency as one of the patient illness-related factors that is considered a stressor. Patients with lower functional abilities would require more physical assistance which may lead to fatigue, a symptom commonly reported

TABLE 1. Socio-demographics profile and illness characteris of the breast cancer patients according to the stress category among care givers

Variable	Normal	Stress	Test	p-value
Age (years)	98 (53.99±10.73)	32 (47.88±9.65)	t test (OR=0.945, CI=0.901-0.991)	0.05
Race				
Malay	71 (54.6%)	23 (17.7%)	Chi-square	0.558
Non-Malay	27 (20.8%)	9 (6.9%)		
Marital status				
Married	86 (66.2%)	29 (22.3%)	Chi-square	0.469
Not married	12 (9.2%)	3 (2.3%)		
Education				
Non-tertiary	85 (65.4%)	28 (21.5%)	Chi-square	0.590
Tertiary	13 (10%)	4 (3.1%)		
Occupation				
Employed	23 (17.7%)	11 (8.5%)	Chi-square	0.182
Unemployed	75 (57.7%)	21 (16.2%)		
Income				
No income	65 (50%)	20 (15.4%)	Chi-square	0.93
<RM2000 monthly	22 (16.9%)	8 (6.2%)		
>RM2000 monthly	11 (8.5%)	4 (3.1%)		
Cancer severity				
Mild (Stage 1)	12 (9.2%)	2 (1.5%)	Chi-square	0.636
Moderate (Stage 2 and 3)	52 (40%)	18 (13.8%)		
Severe (Stage 4)	34 (26.2%)	12 (9.2%)		
Treatment type				
Active	52 (40%)	22 (16.9%)	Chi-square	0.088
Outpatient	46 (35.4%)	10 (7.7%)		
Illness duration (month)	32	98	Mann-Whitney U	0.324
Treatment duration				
Daily to 3-weekly	53 (40.8%)	23 (17.7%)	Chi-square	0.181
2 to 4-monthly	25 (19.2%)	6 (4.6%)		
> 4-monthly	20 (15.4%)	3 (2.3%)		
ECOG score				
0-1	64 (49.2%)	13 (10%)	Chi-square (OR = 3.79, CI= 1.37- 10.48)	0.025
2	21 (16.2%)	9 (6.9%)		
3-4	13 (10%)	10 (7.7%)		

Chi square analysis used was Pearson's Chi-square test

by stressed out caregivers (Gaugler et al. 2008; Osse et al. 2006). Lower functional abilities of the patients may also be an indicator that their cancer is at an advanced stage. Patients in stage 4 of the illness could be bedridden thus requiring more time to be spent on caring for them, including to the point of assisting with their adaptive daily living (ADL).

Caregivers who did not share their care-giving burden were 2.8 times more likely to become stressed. Wagner et al. (2011) found that husbands who report persistent domestic role strain due to not sharing their care-giving burden are at high risk of continued psychological distress (including stress) following their wives' breast cancer treatment. Greater levels of physical strain were significantly associated with greater care-giving burden

among other things (Kim & Schulz 2008). Caregiver's emotional stress was also found to be significantly associated with greater care-giving burden (Kim & Schulz 2008). Shared care-giving was found to be protective as it is a major source of social support to the caregivers (Balneaves et al. 2007; Hoga et al. 2008). Shared care-giving can reduce the stress among the caregivers in many ways. Care-giving has been associated with burden from having to carry out numerous tasks ranging from cooking and cleaning to managing patient's symptoms (Bakas et al. 2001), thus, the ability to share these tasks with others will reduce the burden of the primary caregiver. This may lead to more time-off from care-giving, therefore, allowing time for caregivers to engage in their own leisure activities and to look after their own health. Problems in finding time

TABLE 2. Socio-demographics and health characteristics of care givers according to the stress category

Variable	Normal	Stress	Test	p-value
Age (years)	98(43.41±15.61)	32 (40.97±10.27)	0.401	t test
Sex				
Male	59 (45.4%)	20 (15.4%)	Chi-square	0.494
Female	39 (30%)	12 (9.2%)		
Race				
Malay	71 (54.6%)	23 (17.7%)	Chi-square	0.550
Non-Malay	27 (20.8%)	9 (6.9%)		
Marital status				
Married	63 (48.5%)	22 (16.9%)	Chi-square	0.407
Not married	35 (26.9%)	10 (7.7%)		
Education				
Non-tertiary	68 (52.3%)	24 (18.5%)	Chi-square	0.357
Tertiary	30 (23.1%)	8 (6.2%)		
Occupation				
Employed	57 (43.3%)	23 (17.7%)	Chi-square	0.119
Unemployed	41(31.5%)	9 (6.9%)		
Income				
No income	21 (16.2%)	8 (6.2%)	Chi-square	0.801
<RM2000 monthly	40 (30.8%)	11 (8.5%)		
>RM2000 monthly	37 (28.5%)	13 (10%)		
Relationship to patient				
Spouse	44 (33.8%)	17 (13.1%)	Chi-square	0.504
Children	42 (32.3%)	10 (7.7%)		
Others	12 (9.2%)	5 (3.8%)		
Medical illness				
Absent	66 (50.8%)	21 (16.2%)	Chi-square	0.510
Present	32 (24.6%)	11 (8.5%)		
Duration of caregiving				
>20 h/week	40 (30.8%)	5 (3.8%)	Chi-square	0.007
< 20 h/week	58 (44.6%)	27 (20.8%)	(OR= 3.724, CI = 1.32 - 10.49)	
Dependants				
No other dependant	40 (30.8%)	10 (7.7%)	Chi-square	0.226
Other dependants	58 (44.6%)	22 (16.9%)		
Proximity to hospital				
Outside KlangValley	47 (36.2%)	18 (13.8%)	Chi-square	0.271
Within Klang Valley	51 (39.2%)	14 (10.8%)		
Shared caregiving				
No	74 (56%)	16 (12.3%)	Chi-square	0.007
Yes	24 (18.5%)	16 (12.3%)	(OR= 3.083, CI = 1.342 - 7.085)	
Perceived social support				
Significant others	98	32	Mann-Whitney U	0.324
Family	98	32	Mann-Whitney U	0.712
Friends	98	32	Mann-Whitney U	0.340

Chi square analysis used was Pearson's Chi-square test

for themselves have been reported by 50% of caregivers of cancer patients, especially among caregivers in the younger age group (Osse et al. 2006).

Finally, it was found that caregivers who looked after older patients are less likely to be stressed. Sammarco (2001) wrote that young women are known to be handling

multiple roles such as being a wife, mother, career woman and completing education. Hence, a diagnosis of life threatening illness such as cancer would render them unable to perform these duties well due to the limitations caused by the illness. That is when the caregivers have to take over most of the patients' responsibilities. Sammarco

TABLE 3. Logistic regression analysis of independent variables on caregiver's stress

Variables	B	S.E.	Wald	Df	Sig.	Exp (B)	95% C.I. for Exp(B)	
							Lower	Upper
Patient's age	-.057	.024	5.506	1	.037	.956	.916	.997
Patient's functionality (ECOG score)	1.904	.737	6.681	1	.010	6.714	1.585	28.448
Sharing of care-giving burden	1.033	.516	4.007	1	.045	2.810	1.022	7.727

also mentioned that breast cancer patients who are married experience greater emotional stress due to the impact of the illness on their intimate relationship with their spouse. The emotional stress in the patient will lead to emotional stress in the caregiver as what has been found in many studies on the mutuality of psychological morbidities in cancer patients and their caregivers (Bambauer et al. 2006; Northouse et al. 2002).

There are several limitations in this study. The major limitation is that it was cross-sectional in design, whereby being conducted at one point of time; no causal relationship can be inferred between the outcomes and the variables. A prospective study may have been a better choice. Another important limitation of this study is the application of non-random sampling method within a convenience samples frame which could create sampling bias, resulting in over- or under-representation of certain members of the study population (Levin 2006). The various issues with sampling deemed the results unsuitable to be generalized to the whole population. Apart from that, a smaller sample size could have hampered the study with wide confidence intervals and smaller effect size. This study could also not escape from response bias. This was in the form of over-representation and non-responders, whereby the rate of the latter was quite significant, that is, 25%. Another limitation was the use of DASS-21 which has not been validated with a caregiver population sample. Hence, the prevalence rates must be viewed with caution. The self-rating scales used in this study could also introduce information bias into the study. This study was also faced with the dilemma of having a gold-standard definition for caregivers. Caregiving in breast cancer is a massive area with numerous possible associative factors for psychological morbidities. This study could not consider some of the many other factors that may influence the outcomes. Several of the variables in this study were also not well-defined, such as, shared care-giving and patient's functional status.

Despite the limitations, this study has its fair share of strengths, namely, that it was conducted at the national centre for oncologic treatment in Malaysia which receives patients from various socio economic classes. The strength of this study was that it focused solely on one group of cancer patients, which was breast cancer patients, therefore ensuring a homogenous group of subjects.

## CONCLUSION

There are several implications from the findings of this study. One major point is that there should be awareness among medical personnel about the high likelihood of stress among the family caregivers of breast cancer patients and a heightened sensitivity to the caregivers' emotional condition. The caregivers should have easy access to mental health services. There is a need for respite care facilities in order to relieve the caregivers from constant care-giving burden and stress. Support groups for the caregivers of breast cancer patients need to be realized as it is a means for providing, among others, emotional strength to the caregivers in carrying out their responsibilities.

If these suggestions can be put into practice, the well-being of caregivers will be better taken care of. In a way, it is hoped that the status of caregivers will be raised in the eyes of society.

## ACKNOWLEDGEMENTS

For the breast cancer patients and their caregivers who participated in this study, your courage and strength continued to be the source of inspiration for many.

## REFERENCES

- Abdullah, N.H. & Yip, C.H. 2003. Spectrum of breast cancer in Malaysian women: Overview. *World Journal of Surgery* 27(8): 921-923.
- Awadalla, A.W., Ohaeri, J.U., Gholoum, A., Khalid, A.O., Hamad, H.M. & Jacob, A. 2007. Factors associated with quality of life of outpatients with breast cancer and gynecologic cancers and their family caregivers: A controlled study. *BMC Cancer* 7: 102.
- Bakas, T., Lewis, R.R. & Parson, J.E. 2001. Caregiving tasks among family caregivers of patients with lung cancer. *Oncology Nursing Forum* 28: 847-854.
- Balneaves, L.G., Bottorf, J.L., Grewal, S.K., Naidu, P., Johnson, J.L. & Howard, A.F. 2007. Family support of immigrant Punjabi women with breast cancer. *Family & Community Health* 30(1): 16-28.
- Bambauer, K.Z., Zhang, B., Maciejewski, P.K., Sahay, N., Pirl, W.F., Block, S.D. & Prigerson, H.G. 2006. Mutuality and specificity of mental disorders in advanced cancer patients and caregivers. *Social Psychiatry Psychiatric Epidemiology* 41(10): 819-824.
- Barry, G.M. 2010. Caregiver stress: It's real, and its impact can be severe; How to avoid the epidemic. *BusinessWest* p.58.

- Carey, P.J., Oberst, M.T., McCubbin, M.A. & Hughes, S.H. 1991. Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncology Nursing Forum* 18(8): 1341-1348.
- Center on Aging Society. 2005. *How do family caregivers fare? A closer look at their experiences.* (Data Profile, Number 3). Washington, DC: Georgetown University.
- Covinsky, K.E., Goldman, L., Cook, E.F., Oye, R., Desbiens, N., Reding, D., Fulkerson, W., Connors, A.F. Jr., Lynn, J. & Phillips, R.S. 1994. The impact of serious illness on patients' families. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *JAMA* 272(23): 1839-1844.
- Formica, V., Pellegrino, R., Portarena, I., Mariotti, S. & Roselli, M. 2008. Caregiver distress in the early phases of cancer disease. *Annals of Oncology* 19(9): ix120.
- Gaugler, J.E., Hanna, N., Linder, J., Given, C.W., Tolbert, V., Kataria, R. & Regine, W.F. 2005. Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. *Psychooncology* 14(9): 771-785.
- Gaugler, J.E., Linder, J., Given, C.W., Kataria, R., Tucker, G. & Regine, W.F. 2008. The proliferation of primary cancer caregiving stress to secondary stress. *Cancer Nursing* 31(2): 116-123.
- Hoga, L.A.K., Mello, D.S., Aretuzza, R. & Dias, F. 2008. Psychosocial perspectives of the partners of breast cancer patients treated with a mastectomy - an analysis of personal narratives. *Cancer Nursing* 31(4): 318-325.
- Kim, Y. & Schulz, R. 2008. Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health* 20(5): 483-503.
- Levin, K.A. 2006. Study design III: Cross-sectional studies. *Evidence-Based Dentistry* 7: 24-25.
- Lim, G.C.C., Rampal, S. & Halimah, Y. 2008. *Cancer Incidence in Peninsular Malaysia, 2003 – 2005.* Kuala Lumpur: National Cancer Registry, Ministry of Health Malaysia.
- Lovibond, S.H. & Lovibond, P.F. 1995. *Manual for the Depression Anxiety Stress Scale.* 2<sup>nd</sup> Ed. Sydney: Psychology Foundation of Australia.
- Marks, N., Lambert, J.D. & Choi, H. 2002. Transitions to caregiving, gender, and psychological well-being: A prospective U.S. national study. *Journal of Marriage and Family* 64: 657-667.
- Mellon, S., Northouse, L.L. & Weiss, L. 2006. A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing* 29(2): 120-131.
- Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R.J. & van den Bos, G.A. 1998. Cancer and caregiving: The impact on the caregiver's health. *Psychooncology* 7(1): 3-13.
- Northouse, L.L. 1995. The impact of cancer in women on the family. *Cancer Practice* 3: 134-142.
- Northouse, L.L., Templin, T., Mood, D. & Oberst, M. 1998. Couples' adjustment to breast cancer and benign breast disease: A longitudinal analysis. *Psychooncology* 7(1): 37-48.
- Northouse, L.L., Mood, D., Kershaw, T., Schafenacker, A., Mellon, S., Walker, J., Galvin, E. & Decker, V. 2002. Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology* 20(19): 4050-4064.
- Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T. & Carbone, P.P. 1982. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology* 5(6): 649-655.
- Osse, B.H., Vernooij-Dassen, M.J., Schadé, E. & Grol, R.P. 2006. Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing* 29(5): 378-388.
- Pinquart, M. & Sorensen, S. 2003. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging* 18(2): 250-267.
- Rabin, E.G., Heldt, E., Hiraakata, V.N., Brittelbrunn, A.C., Chachamovich, E. & Fleck, M.P. 2009. Depression and perceptions of quality of life of breast cancer survivors and their male partners. *Oncology Nursing Forum* 36(3): E153-158.
- Ramli, M., Mohd Ariff, F. & Zaini, Z. 2007. Translation, validation and psychometric properties of Bahasa Malaysia version of the depression anxiety and stress scales (DASS). *ASEAN Journal of Psychiatry* 8(2): 82-89.
- Rivera, H. 2009. Depression symptoms in cancer caregivers. *Clinical Journal of Oncology Nursing* 13(2): 195-202.
- Sammarco, A. 2001. Psychosocial stages and quality of life of women with breast cancer. *Cancer Nursing* 24(4): 272-277.
- Schulz, R. & Beach, S.R. 1999. Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA* 282(23): 2215- 2219.
- Wagner, C.D., Tanmoy Das, L., Bigatti, S.M. & Storniolo, A.M. 2011. Characterizing burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. *Cancer Nursing* 34(4): E21-30.
- Weitzner, M.A., Haley, W.E. & Chen, H. 2000. The family caregiver of the older cancer patient. *Hematology Oncology Clinics of North America* 14: 269-281.
- Zainal, A.O., Zainudin, M.A. & Nor Saleha, I.T. 2006. *Malaysian Cancer Statistics – Data and Figure, Peninsular Malaysia, 2006.* Kuala Lumpur: National Cancer Registry, Ministry of Health Malaysia.
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Received: 3 July 2012

Accepted: 23 July 2012