

## RESEARCH ARTICLE

# Anxiety Disorders in Family Caregivers of Breast Cancer Patients Receiving Oncologic Treatment in Malaysia

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## Abstract

**Background:** Anxiety is recognized as a normal psychological reaction of those caring for cancer patients. However, anxiety disorders in caregivers may interfere with their care-giving role and require further clinical attention. **Objectives:** To determine the prevalence and associated factors of anxiety disorders among caregivers of breast cancer patients receiving oncologic treatment in Kuala Lumpur Hospital. **Methodology:** A cross-sectional study was conducted on 130 caregiver-patient dyads, recruited by non-random sampling at Kuala Lumpur Hospital. Data were collected in 2 stages: 1) the caregivers were screened for psychological distress using the Depression, Anxiety, Stress, Scale (DASS-21) while other related factors for the patients and their caregivers were obtained; 2) the identified distressed caregivers (n=64) were then administered the Mini International Neuropsychiatric Interview (MINI) to diagnose anxiety disorders. **Results:** A total of 11.5% (n=15) of the caregivers reported suffering from anxiety disorders. Bivariate analysis found duration of caregiving (OR=3.31; CI=2.21-11.93), shared caregiving (OR=4.07; CI=1.34-12.36), and patients' treatment type (OR=3.42; CI=1.92-12.76) were significantly associated with anxiety disorders (p value <0.05), with shared caregiving and patient's treatment type remaining significant using logistic regression (p value < 0.05, R<sup>2</sup> = 0.255). **Conclusions:** Every one in ten of the caregivers in this study had a diagnosable anxiety disorder, associated with certain care-giving factors and patients' treatment. This should alert clinicians to such risk and indicates psychological support needs for family caregivers.

**Keywords:** Family caregivers- anxiety disorders- psycho oncology- cancer

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## Introduction

Cancer is associated with high mortality rate that upon diagnosis, many experience fear, anxiety and depression (Lethborg et al., 2003; Turner et al., 2005; Bevans and Sternberg, 2012). In Malaysia, breast cancer is reported to be the most prevalent cancer (Zainal et al., 2006) with a lifetime diagnosis rate of about 5% (Hisham and Yip, 2003; Yip et al., 2006; Lim et al., 2008;). Despite its relatively good survival rate (Coleman et al., 2011), many Malaysian patients regrettably sought oncologic treatment only at the later stages (Abdullah and Yip, 2003). This would compromise the survival rate and demands greater care and support from the family caregivers who are already emotionally vulnerable.

Anxiety has been commonly described among the family caregivers of cancer patients (Nijboer et al., 1998; Maguire et al., 1999; Grunfeld et al., 2004; McLean and Jones, 2007) whereby between 15 and 50% of patients and their spouses suffered significant psychological distress (McLean and Jones, 2007). A study assessing the needs

of the caregivers of cancer patients reported that fear of an unpredictable future was the most prevalent problem for the caregivers (80%) while 48% of the caregivers experienced anxiety for their own health (Osse et al., 2006).

In Malaysia, the prevalence of probable anxiety among the caregivers of cancer patients was 48.6% with caregiver's age as the main factor associated with anxiety (Ambigga et al., 2005). Unfortunately, despite its high prevalence, the distress was unrecognized hence the poor support and care for the caregivers. The psychological problems among the caregivers negatively correlate with their quality of life (Heidari et al., 2012). About 1 in 5 caregivers (22%) reported not receiving adequate professional attention for their fear as revealed by Osse et al (2006). Other studies also reported similar findings including not receiving any relief from the caregiving burden (Maguire et al., 1999) and inadequate psychiatric consultation for the patients' family (Akechi et al., 2001; Asai et al., 2008).

Being a family caregiver requires one to carry multiple

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responsibilities for the cancer patients. This encompasses taking care of the symptoms, treatment and its adversities, other practicalities like transportation, financial matter and house chores but also the patients' psychological reactions to distress (Carey et al., 1991). Bakas et al., (2001) identified that supporting the patients' emotion and managing their symptoms are the hardest tasks for the family caregivers. Furthermore, the phase during which the patients were undergoing therapy has been recognized as the most stressful time for the family caregivers (Northouse, 1995).

In fact, studies have shown that like the cancer patients, the caregivers were also at risk of psychological problems (Heidari et al., 2012; Nik Ruzyanei et al., 2013). A study by Northouse et al., (2002) found that caregivers of recurrent breast cancer patients had significantly poorer mental health than the normal population and experienced emotional distress much worse than the cancer patients. (Bambauer et al., 2006) also found that the caregivers had increased risk of having psychiatric morbidity when the cancer patients met the criteria for a diagnosable psychiatric illness. When the caregivers reported emotional stress, studies showed that the patients' quality of life including the physical and psychological aspects is compromised (Northouse et al., 2002; Mellon et al., 2006; Rabin et al., 2009). Moreover, (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 (Schulz and Beach 1999).

Considering the high probability of anxiety among the caregivers, it is important to determine the extent of proportion of those who required clinical attention. Many studies screened for anxiety symptoms, but few used diagnostic tools such as The Mini-International Neuropsychiatric Interview (MINI) (Sheehan et al., 1998) and Structured Clinical Interview for the DSM-IV (DASS) to determine presence of anxiety as clinical diagnosis.

Therefore, this study aimed to determine the rates of anxiety disorders and its associated factors in the caregivers of the breast cancer patients who were receiving oncologic treatment. To the authors' knowledge, this is the first study in Malaysia that aimed to determine the anxiety disorders specifically focusing on the family caregivers of breast cancer patients. The findings would identify those who were at risk and heighten the awareness for the health professionals managing breast cancer patients to incorporate holistic care.

## Materials and Methods

### *Study design, sampling and operational definitions*

A cross-sectional study was done on family caregivers of inpatients and outpatients who were receiving treatment for breast cancer. The patients were recruited from all of those who attended The Institute of Radiotherapy and Oncology of Kuala Lumpur Hospital, a main referral centre for cancer in Malaysia during a six-month study period. Oncology treatment for breast cancer encompass surgery, chemotherapy, radiotherapy; either single or in any combination and also maintenance therapy with

hormonal drugs such as tamoxifen for some, to prevent recurrences.

The family caregivers were related to the patients either by blood or by marriage, and recognized by the patients as the one who provided most of the informal and unpaid care (Northouse, 1995; Nik Ruzyanei et al., 2013; Mellon et al., 2006). Beside this criterion, both the patients and the caregivers must be conversant in either English or Malay language. The exclusion criteria were caregivers who were younger than 18 years old and not family members.

### *Sample Size*

The sample size for this study was calculated using the formula to estimate a population proportion with specified absolute precision at 0.05% for 80% statistical power (Lwanga and Lemeshow, 1991) based on the prevalence of psychiatric morbidity of 11% in Malaysia (The Third National Health and Morbidity Survey, 2006). This yields a total of 150 caregiver-patient dyads. However, only 130 was available during the duration of the study.

### *Data Collection*

The patients were explained about the study and those who agreed to participate were asked to identify their main family caregiver. The study was then described to the patient and the family caregiver. Both the patients and their caregivers were asked to sign the consent forms. The patients' data were mainly obtained from their medical record while the caregivers had to complete three self-administered questionnaires including their socio-demography and the caregiving factors, the Multi-dimensional Perceived Social Support (MSPSS) and Depression, Anxiety and Stress Scale (DASS-21) (DASS). Consequently, those screened positive for psychological distress with DASS-21 (DASS) were interviewed using MINI (Sheehan et al., 1998) to determine the presence of anxiety disorder.

### *Study measures*

The patients were assessed using self-rated socio-demographic questionnaire and Eastern Cooperative Oncology Group (ECOG) Performance Status scales. The ECOG assesses how cancer affects the patient's daily living abilities (Oken et al., 1982). It scores from 0 to 5 points scale ranging from fully active person to complete disability and score 5 if one dies (Oken et al., 1982).

Meanwhile, the caregivers were assessed using self-rated socio-demographic questionnaire, The Multi-dimensional Perceived Social Support Scale (MSPSS) and Depression Anxiety Stress Scale (DASS-21) (DASS). MSPSS measures perceived social support from three sources which are family, friends, and significant others. It has excellent internal consistency with alphas of 0.91 for the total scale and good test-retest reliability as well. MSPSS has good factorial validity and has good concurrent validity when correlating with depression (Zimet et al., 1988). The Malay version of MSPSS has been translated and validated by (Ng et al., 2010).

DASS-21 (Oken et al., 1982) captures symptoms of depression, anxiety and stress. The DASS-21 (DASS)

has been translated into Malay language. The internal consistency, test-retest reliability and validity of case-identification had been established for this translated version (Musa et al., 2007). It is commonly used among Malaysian population in clinical and in the community (Ramli et al., 2009; Loh et al., 2009).

Those who were found to have anxiety symptoms were reassessed further using MINI Neuropsychiatric Interview (MINI) to obtain diagnosis of anxiety disorders. MINI (Sheehan et al., 1998) is a brief structured interview for the major Axis 1 psychiatric disorders in DSM-IV (Sheehan et al., 1998) and ICD-10. It has high validation and reliability scores whereby when compared to SCID-P, MINI (Sheehan et al., 1998) was found to be 96% sensitive and 88% specific while comparison with CIDI produced 94% sensitivity and 79% specificity.

#### *Statistical analysis*

The data was analyzed by using Statistical Package for the Social Science (SPSS) program version 18.0 (SPSS, Chicago). The associations between socio-demographic characteristics, clinical factors and anxiety disorder were analyzed using chi-square and t-test statistics. A p-value of less than 0.05 was considered as significant. Logistic regression analysis was performed to determine predictors of anxiety disorders.

#### *Ethical aspects*

Ethical approval was granted by the Research and Ethics Committee, UKMMC and the Ministry of Health (MOH) Medical Research and Ethics Committee (MREC). Those who were found to have anxiety disorders were offered available sources of help including referral for psychiatric consultation.

## **Results**

#### *Study respondents*

Out of 173 breast cancer patients eligible to participate in this study, a total of 130 patient-family caregiver dyads participated. The other 43 subjects were withdrawn due to the following reasons: 12 patients refused to participate, 19 caregivers were absent for assessment, 6 caregivers were not the primary caregivers, 5 did not understand both English or Malay languages and 1 patient did not have a family caregiver.

#### *Overall DASS results*

In this study, a total of 64 caregivers (49.2%) of the 130 participants were found to have psychological distress i.e. they scored positively in either one or more domains of DASS-21 (Northouse, 1995). Twenty-four out of 64 subjects (18.5%) screened positively in all the three scales of stress, anxiety and depression; 6 subjects (4.6%) scored positively in both depression and anxiety domains; 3 subjects (2.3%) scored positively in both depression and stress domains and 11 subjects (8.5%) scored positively in depressive domain alone. Subjects who scored positively in anxiety domain alone and stress domain alone were 14 (10.8%) and 4 (3.1%) respectively while those who scored positive on both stress and anxiety were 2 (1.5%).

Therefore, a total of 48 caregivers of the 130 participants (36.9%) were found to have probable anxiety i.e. those who screened positive in anxiety domain out, either alone or in combination with the other domain(s).

#### *The rates of anxiety disorders*

For diagnosis of anxiety, all the 64 caregivers who were found to have scored positively in either one or more domains of DASS-21 (DASS) were further assessed with MINI (Sheehan et al., 1998). 11.5% (n=15) were diagnosed to have anxiety disorders, where 6.2% (n=8) had generalized anxiety disorder, 4.6% (n=6) diagnosed to have panic disorder, and 0.8% (n=1) had social phobia.

#### *Factors associated with anxiety disorders among caregivers*

##### *The patients' factors*

Table 1 showed that the patients' treatment type (OR=3.42; CI=1.92-12.76) was the only patients' factor that was significantly associated with anxiety disorders (p value <0.05), whereby caregivers who had anxiety disorder were 3 times more likely to care for patients who underwent active treatment (chemotherapy, radiotherapy or palliative therapy) (n=12, 9.2%) versus (n=3, 2.3 %). This remained significant after controlling for confounding factor using logistic regression (p value < 0.05, R<sup>2</sup> = 0.255), as shown in table 3.

##### *The caregivers' factors*

Bivariate analysis found duration of caregiving (OR=3.31, CI=2.21-11.93) and shared caregiving (OR=4.07, CI=1.34-12.36), were significantly associated with anxiety disorders (p value <0.05) as shown in Table 2. However, only shared caregiving remained significant when controlled for confounding effect (p value < 0.05, R<sup>2</sup> = 0.255), as shown in table 3.

## **Discussion**

This study found that more than a tenth (11.5%, n=15) of the family members who were primarily involved in caring for breast cancer patients had anxiety disorders. Specifically, 8 caregivers (6.1%) had generalized anxiety disorder, 6 were (4.6%) diagnosed to have panic disorder, and one (0.8%) had social phobia. Earlier prevalent study conducted in the West found similar rate although the rate for specific disorder differed. (Vanderwerker et al., 2005) found 13% of caregivers had a diagnosable anxiety disorders with 8% had panic disorder, 4% posttraumatic stress disorder and 3.5% generalized disorder. (Drabe et al., 2008) studied the wives of head and neck cancer patients and found 15.5% had anxiety disorder, with majority had agoraphobia.

This study, as expected, reported a much higher prevalence rate of those screened positive for anxiety symptoms (caseness) (36.9%; n=48) compared to the rate of diagnosable anxiety disorders (case) (11.5%; n=15). Nevertheless, this study reported a lower prevalence of those with anxiety symptoms compared to a previous similar study in Malaysia conducted by Ambigga et al. (2005) which reported almost half of the study population

Table 1. Association between Caregiver's Anxiety Disorders and the Breast Cancer Patients' Socio-Demographic and Illness Characteristics of (n=130)

Variables value	Anxiety Disorders	No Anxiety Disorders	Test	p value
Age (years)	15 (49.93±10.33)	115 (52.82±10.82)	0.976 <sup>a</sup>	0.623
Sex				
Male	0 (0.0%)	1 (0.9%)	0.131 <sup>b</sup>	0.717
Female	15 (100.00%)	114 (99.1%)		
Race				
Malay	9 (6.9%)	85 (65.4%)	1.283 <sup>b</sup>	0.257
Non-Malay	6(4.6%)	30 (23.1%)		
Marital status				
Married	12(9.23%)	103 (79.2%)	1.189 <sup>b</sup>	0.275
Not married	3(2.31%)	12 (9.23%)		
Education				
Non-tertiary	15 (11.5%)	98 (75.4%)	2.551 <sup>b</sup>	0.110
Tertiary	0 (0.0%)	17 (13.1%)		
Occupation				
Employed	5 (3.85%)	29 (22.31%)	0.453 <sup>b</sup>	0.501
Unemployed	10(7.7%)	86 (66.2%)		
Income				
No income	10 (7.7%)	75 (57.7%)	2.734 <sup>b</sup>	0.255
<RM2000 monthly	5 (3.8%)	25(19.2%)		
>RM2000 monthly	0(0.0%)	15 (11.5%)		
Cancer severity				
Mild (Stage 1)	0 (0.0%)	14 (10.8%)	3.386 <sup>b</sup>	0.184
Moderate (Stage 2 and 3)	11 (8.5%)	59 (45.4%)		
Severe (Stage 4)	4 (3.1%)	42 (32.3%)		
Treatment type				
Active	12 (9.2%)	62 (47.7%)	3.987 <sup>b</sup>	0.047*
	(OR=0.49, CI=0.24-0.99)			
(Chemotherapy, Radiotherapy, Palliative)				
Outpatient	3 (2.3%)	53 (40.8%)		
(Hormonal therapy)				
Illness duration (month)	15 (29.93±30.33)	115(31.35±39.71)	-0.025 <sup>a</sup>	0.411
Treatment duration				
Daily to 3-weekly	12 (9.2%)	64 (49.2%)	3.297 <sup>b</sup>	0.192
2 to 4-monthly	2 (1.5%)	29 (22.3%)		
> 4-monthly	1 (0.77%)	22 (16.92%)		
ECOG score				
0-1	8 (6.2%)	69 (53.1%)	1.055 <sup>b</sup>	0.590
2	5 (3.8%)	25 (19.2%)		
03-4	2 (1.5%)	21 (16.2%)		

<sup>a</sup>, t-test; <sup>b</sup>, Pearson's Chi-square test

(48.6%) had anxiety symptoms. This could be due to the differences in the screening tools used and time lag between the two studies. The main difference though was the population studied. While this study focused on families of breast cancer inpatients and outpatients; Ambigga et al. (2005) included a more heterogenous group of oncologic outpatients that consisted of 26 types of cancers. Nevertheless, the prevalence of the positively screened anxiety symptoms in this study was within the reported range of psychological distress among family

of cancer patients (McLean and Jones, 2007; Park et al., 2013).

Both the patient factor and care-giving factor namely the patient's treatment type and sharing of care respectively, had significant association with anxiety disorders among the family caregivers. It was found that the caregivers of patients who were receiving active treatments such as chemotherapy and radiotherapy had increased rate of anxiety disorders than those caring for patients receiving outpatient treatment. Active

Table 2. Association between Caregiver's Anxiety Disorders and Their Socio-Demographic, Caregiving Factors, and Perceived Social Support (n=130)

Variable	Anxiety Disorders	No Anxiety Disorders	Test	p value
Age (years)	15 (43.03±15.14)	115 (41.01±7.92)	0.493 <sup>a</sup>	0.623
Sex				
Male	9 (6.9%)	70 (53.8%)	0.004 <sup>b</sup>	0.948
Female	6 (4.6%)	45 (34.6%)		
Race				
Malay	12 (9.23%)	82 (63.08%)	1.283 <sup>b</sup>	0.257
Non-Malay	11 (8.46%)	25 (19.23%)		
	(OR=2.39 , CI=1.09-5.25)			
Marital status				
Married	9 (6.9%)	76 (58.5%)	0.217 <sup>b</sup>	0.641
Not married	6 (4.6%)	19 (30.0 %)		
Education				
Non-tertiary	10 (7.7%)	82 (63.1%)	0.138 <sup>b</sup>	0.710
Tertiary	5 (3.8%)	33 (25.4%)		
Occupation				
Employed	11 (8.5%)	69 (53.1%)	0.997 <sup>b</sup>	0.318
Unemployed	4 (3.1%)	46 (35.4%)		
Income				
No income	3 (2.3%)	26 (20.%)	0.488 <sup>b</sup>	0.784
<RM2000 monthly	5 (5.4%)	46 (35.4%)		
>RM2000 monthly	7 (5.4%)	43 (33.1%)		
Relationship to patient				
Spouse	6 (4.6%)	55 (42.3%)	0.795 <sup>b</sup>	0.672
Children	6 (4.6.69%)	46 (35.4%)		
Others	3 (2.31%)	14 (10.77%)		
Medical illness				
Absent	11 (8.5%)	76 (58.5%)	0.315 <sup>b</sup>	0.575
Present	4(3.1%)	39 (30.%)		
Duration of caregiving				
> 20 hours/week	2 (1.5%)	43 (33.1%)	3.393 <sup>b</sup>	0.065
< 20 hours/week	13 (10 %)	72 (55.4%)		
	(OR=2.72 CI=1.28-5.79)			
Dependants				
No other dependant	4 (3.1%)	46 (35.4%)	0.997 <sup>b</sup>	0.318
Other dependant	11 (8.5%)	69 (53.1%)		
Proximity to hospital				
Outside Klang Valley	5 (3.8%)	60 (46.2%)	1.884 <sup>b</sup>	0.170
Within Klang Valley	10 (7.7%)	55 (42.3%)		
Shared caregiving				
No	9 (6.92%)	31 (23.85%)	6.801 <sup>b</sup>	0.009*
Yes	6 (4.6%)	84 (64.6%)		
Perceived social support (mean rank)				
Significant others	15(75.03)	115(64.26)	-1.055 <sup>c</sup>	0.292
Family	15(66.63)	115(65.35)	-0.124 <sup>c</sup>	0.901
Friends	15(65.23)	115(65.23)	-0.231 <sup>c</sup>	0.818

<sup>a</sup>, t-test; <sup>b</sup>, Pearson's Chi-square test; <sup>c</sup>, Mann-Whitney U (z score)

treatment was known to pose difficulties to the caregivers particularly in terms of managing the side effects of treatment (Northouse,1994; Mystakidou et al., 2007).

(Mystakidou et al., 2007) also found that caregivers of patients who were receiving radiotherapy were at risk for hopelessness and depression; which would increase their

Table 3. Logistic Regression Analysis of Independent Variables on Anxiety Disorders

Variables	B	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I. for Exp(B)	
							Lower	Upper
Patient's Treatment Type	1.515	0.714	4.505	1	0.034	4.55	1.123	18.438
Shared Caregiving	-1.839	0.609	9.106	1	0.003	0.159	0.048	0.525

vulnerability to anxiety.

This study showed that caregivers who did not share their care-giving role with others had increased rate of anxiety disorders. This is in accordance with most study findings where shared care-giving provided a major source of social support to the caregivers hence protective to the caregivers of psychological adversities (Hoga et al., 2008; Balneaves et al., 2007). Lingler et al. (2008) nevertheless, demonstrated that shared care-giving can be a possible stressor to the caregivers particularly when involving other family caregivers. For example, the primary caregiver would be less empowered as they would have to consider the opinion of the other co-caregivers in making decision about patient's treatment or about deciding for the amount of support to be given by each caregiver to the patient. It was also raised that shared care-giving was not a well defined variable and difficult to be quantified (Lingler et al., 2008). For example, the primary caregivers could carry the bulk of the burden with minimal input from the co-caregivers but still considered as sharing the care-giving role due to the presence of others.

This study has several limitations. Mainly, it was cross-sectional in design that the direction of the factors and the risk factors of anxiety disorders could not be established. Another important limitation was the small sample size which limited the power of the study to detect any other factors particularly involving the care-giving process such as duration of care that could have significance to the anxiety disorders. It also has limited generalisability as the study population was derived from the patients and caregivers from one treatment centre albeit the largest in the country. Consequently, it excluded those who were receiving treatment from other smaller oncology centres including private hospitals.

This study found more than a tenth of the caregivers had anxiety disorders, associated with both the patients' type of treatment and non-shared care-giving. While anxiety has been recognized as a normal psychological reaction of those caring for chronically ill family members, anxiety disorders are debilitating and counterproductive to the care-giving tasks. A multidisciplinary management approach should be extended to those at risk which would directly and inadvertently optimise the treatment care for patients with breast cancer.

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