

# Mental Health Status and Its Associated Factors Among Caregivers of Psychiatric Patients in Kuching, Sarawak

Ivan Vun JS, Cheah WL, Helmy H

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## Authors:

### Cheah Whye Lian

(Corresponding author)

PhD

Department of Community Medicine and Public Health, Faculty of

Medicine and Health Sciences

Universiti Malaysia Sarawak

Malaysia.

E-mail : wlcheah@unimas.my

### Ivan Vun Jan Shui

DrPH

Faculty of Medicine and Health

Sciences, Universiti Malaysia

Sarawak, Malaysia.

E-mail : ivanvun@gmail.com

### Helmy Hazmi

MComMed

Department of Community Medicine

and Public Health, Faculty of

Medicine and Health Sciences

Universiti Malaysia Sarawak

Malaysia.

E-mail : hhelmy@unimas.my

## Abstract

**Introduction:** Caregivers have a high risk of mental health disorders. The quality of patient care is inseparable from the mental health status of caregivers. The objective of this research was to study the mental health status among caregivers of psychiatric patients and its associated factors.

**Method:** A cross-sectional study was conducted among 198 caregivers in Kuching from January till July 2014. The respondents were recruited using systematic sampling and were required to provide information on sociodemographic and environmental factors as well as complete the Hospital Anxiety and Depression Scale (HADS) questionnaire. The data was analysed using the IBM SPSS Statistical Software Version 20.0.

**Results:** The prevalence rates of anxiety and depression among caregivers were 32.8% and 27.8%, respectively. The caregiver's age (OR=0.97, 95% CI = 0.953 - 0.996), the perception of caregiving as an economic burden (OR= 2.70, 95% CI= 1.256 - 5.803) and the dependence of the patient (OR= 2.27, 95% CI= 1.087 - 4.719) were associated with anxiety. A caregiver who was male (OR= 2.21, 95% CI= 1.143 - 4.262), a caretaker who held the perception that a patient was dependent on them (OR=2.53, 95% CI= 1.203 - 5.337) , and a caretaker who lacked stress-coping skills (OR=2.48, 95% CI= 1.030 - 5.973) were found to be significant factors in depression.

**Conclusion:** A high prevalence of probable anxiety and depression among caregivers points to the need to screen caregivers. There is a vital need to train healthcare workers to be able to detect early anxiety and depression. Culturally sensitive research should be carried out for different ethnicity, and improving the support system for caregivers is necessary.

## Introduction

Patients with mental illness are often stigmatized, especially in the Asian countries such as Malaysia.<sup>1</sup> The situation is complicated by multi-cultures, social backgrounds, religions and beliefs.<sup>2</sup> The discrimination against patients also extends to their family members. Based on hospital figures, the prevalence of mental illness in Malaysia in 2000 was 10.7%.<sup>3</sup> This figure was increased to 29.2% by the National Health and Morbidity survey conducted in 2015.<sup>4</sup> Mental health services in Malaysia are relatively young compared to those of the developed countries, but Malaysia has moved towards deinstitutionalization of patients since the 1970s and providing mainly community-based treatment.<sup>5</sup> Patients who are discharged into the community are expected to adapt to society. Many informal caregivers, who are not trained, thus shoulder the responsibility of providing for their care.

Caregiving is a burden that is associated with poor quality of life.<sup>6,7</sup> A local study showed high prevalence rates of depression (29.4%) and

anxiety (48.6%) among caregivers.<sup>8</sup> A survey on the mental health of informal caregivers in Ontario found that caregivers had higher rates of affective (6.3% vs 4.2%) and anxiety (17.5% vs 10.9%) disorders compared to non-caregivers.<sup>9</sup> Furthermore, caregivers of patients with mental illness were found to have high rates of mental health difficulties (>80%) compared to the general population.<sup>10</sup> They experience significantly more caregiving burdens than caregivers of those with other chronic medical illnesses.<sup>11</sup> Factors affecting a person's mental health include persistent socio-economic pressures, rapid social change, stressful work conditions, gender discrimination, social exclusion, unhealthy lifestyle, violence, physical ill-health, human rights violations, and other specific psychological and personality factors.<sup>10,12</sup> For caregivers, the impact of caregiving depends on the type of patient's disability, the stage of the caregiving process, socioeconomic status, social support and the caregiver's stress-coping strategy.<sup>13</sup> Cultural beliefs and practices were also found to be associated with mental health problems in Malaysia.<sup>14</sup>

Both the physical and mental well-being of caregivers inevitably affects the quality of care of the psychiatric patient. In Malaysia, the care of a discharged patient depends on ongoing psychoeducation and close follow ups.<sup>15</sup> There are limited studies on informal caregivers for psychiatric patients in East Malaysia. This study was done to serve as a baseline study of the mental health status among informal caregivers of psychiatric patients and its associated factors. As psychiatric patients are treated in the community, new burdens related to health issues among caregivers may emerge. The findings from this study may serve as a guide for public health specialists in planning programmes to tackle this issue according to the local contexts.

### Materials and Methods

The participants in this study were recruited from Sarawak General Hospital and Sentosa Hospital, two of the major hospitals with the most psychiatric patients in the state of Sarawak. A cross-sectional study was conducted from January to July 2014 at these hospitals, as they are the main admission, discharge and follow up point for patients with psychiatric illnesses in Kuching. Ethical approval was obtained from the ethics committee of the Universiti Malaysia Sarawak (UNIMAS) and National Medical Research Register (ID: NMRR-13-1512-18958). Verbal and written consent were sought from the respondents after they were assured of their anonymity and confidentiality.

Using the lifetime risk of depression among men in the Southeast Asian Region of 7% and a lifetime risk among females of 20%, the sample size for this study was computed using the two-proportion formula in the PS software.<sup>16</sup> With a power of 0.8 and type I error  $\alpha=0.05$ , the calculated sample size was found to be 107 samples per arm, for a total sample size of 214. The final sample size was 224 after including a 5% non-response rate. Systematic sampling was employed whereby the caregiver of every third patient who entered the clinic was recruited. The respondents had to be Malaysian, aged 18 years old and above and been a caregiver for at least six months. Formal caregivers and those who could not understand Malay or English were excluded from the study.

The respondents were required to fill in questionnaires to provide information on their sociodemographic profiles and answer questions pertaining to the individual and environmental factors associated with their mental health.

They were also required to complete the Hospital Anxiety and Depression Scale (HADS)<sup>17</sup> questionnaire. For the latter, the respondents could choose to answer either the English or the validated Malay version.<sup>18</sup> The HADS questionnaire is a screening tool with seven items on both anxiety and depression. Each item can be scored on a four-point Likert scale of 0-3 (not present-considerable), resulting in a minimum score of 0 and maximum score of 21. A score of  $\leq 7$  is considered to be "normal"; 8-10 is considered to be a "mild case", 11-14 a "moderate case", and 15-21 a "severe case" for both anxiety and depression. Generally, a score of  $\geq 8$  is considered to be a "case" for both anxiety and depression. In Malaysia, the Depression Anxiety Stress Scale (DASS) is used widely in health clinics. However, in this study, HADS was chosen, as it has fewer items, performs consistently with DASS, and is sensitive, specific (0.8 for both the anxiety and depression subscales) and reliable (with the reported Cronbach's alphas all exceeding 0.7).<sup>18,19</sup>

The researchers recruited the respondents on clinic days. Respondents who agreed to participate in the study were given the questionnaire to fill out at the clinic. Questions which were unclear were clarified by the researchers in the language familiar to the respondent. A pre-test using 15 respondents was undertaken to test the suitability of the questionnaires for the local context at the out-patient department of Batu Kawa health clinic in Kuching.

The data obtained were checked for inconsistencies, then cleaned, coded, entered and analysed using the IBM SPSS Statistical Software Version 20.0. Descriptive analyses of the sociodemographic, individual and environmental factors and the prevalence of probable anxiety or depression were done via frequencies, means and standard deviations. Univariate analyses were done to select significant variables via univariate tests before entering the variables into multivariate analysis. Multiple logistic regression was applied to determine factors associated with mental health status. Multivariate models were selected by conducting forward and backward LR (likelihood ratio) tests and using the Enter method. Interactions, multicollinearity, assumptions and outliers were considered and investigated. Model fitness was assessed using the ROC (receiver operating characteristic) curve, Hosmer-Lemeshow goodness-of-fit test

and classification table. A p value of <0.05 was considered statistically significant. An odds ratio of more than 1 implies that there is an increased odd of being associated with the condition disorder, while less than one implies otherwise.

### Results

Out of a total of 225 respondents who were invited to participate in the study, only 198 participated, giving a response rate of 88%. Among those who did not participate, 18 did not fulfil the inclusion criteria, and the remaining 9 did not complete the questionnaires for various reasons, such as they found it a hassle to answer the questions while they were engaged in caregiving at the clinic and they refused to answer certain questions.

**Table 1** shows that 54% of the respondents

were female. The mean age of respondents was 42.4 (SD = 13.12), with the youngest being 18 years old and the oldest being 70 years old. The age group 45 – 54 years old had the highest proportion of respondents (25.8%) followed by those in the 35 – 44 age group (25.3%). Only 5.1% of the respondents were aged 65 years and above. However, more than one-tenth (12.1%) were less than 25 years old. The proportions of Chinese and Malay were 36.4% and 33.3% respectively, making up about two-thirds of the total respondents. In terms of religion, most of the respondents were Christians (44.4%), followed by Muslims (34.8%). A majority of the respondents had received at least a primary school education (89.4%), while half of the respondents (54.5%) worked. Most of the respondents (82.8%) reported a low household income of less than RM 2300 per month.

**Table 1.** Sociodemographic characteristics of respondents (N=198).

Variable	n(%)
<i>Gender</i>	
Male	91 (46)
Female	107 (54)
<i>Age Group</i>	
<25	24 (12.1)
25-24	35 (17.7)
35-44	50 (25.3)
45-54	51 (25.8)
55-64	28 (14.1)
>65	10 (5.1)
<i>Ethnicity</i>	
Malay	66 (33.3)
Chinese	72 (36.4)
Iban	24 (12.1)
Bidayuh	31 (15.7)
Other	5 (2.5)
<i>Education status</i>	
Not educated	21 (10.6)
Received at least primary education	177(89.4)
<i>Employment status</i>	
Employed	108 (54.5)
Unemployed	90 (45.5)
<i>Household income (per month)</i>	
<RM2300	164 (82.8)
RM2300-RM7000	30 (15.2)
>RM7000	4 (0.0)

The mean duration of caregiving was 7.8 (SD=7.47) years. More than three-quarters (77.8%) of the informal caregivers were immediate family members, with almost half (46.5%) of these caregivers being the children of the patients and almost one-quarter (24.2%) being the patients' own siblings. The proportion of respondents who resided with the patient was 84.3%. More than half of the respondents (54.5%) were full-time caregivers. Only 12 caregivers reported of having any chronic disease or disability. A total of 79.3% of respondents perceived that the patients could take care of themselves, and 76.3% of respondents reported having familial support or a supportive network. Caregiving was reported to be an economic burden by 18.7% of the respondents. With regards to relieving stress, 86.4% of the respondents reported knowing how to release stress when they were worn out (see **Table 2**).

**Table 2.** Profiles of the caregivers (N=198).

Variable	n(%)
<i>Relationship with the patient</i>	
Immediate family members <sup>1</sup>	91 (46)
Non-immediate family members <sup>1</sup>	107 (54)
<i>Time spent with patient</i>	
Full time	108 (54.5)
Part time	90 (45.5)
Caregiver having disability or chronic illness	12 (6.1)
Caregiver thinks patient is independent	157 (79.3)
Caregiver knows method of stress release	171 (86.4)
Caregiver resides with patient	167 (84.3)
Caregiver has supportive network or familial support	151 (76.3)
Caregiver thinks caregiving is an economic burden	37 (18.7)

<sup>1</sup> Immediate Family Members = parents, siblings, children, spouse. Non-Immediate Family Members = cousins, friends, neighbours and others.

**Table 3** presents the prevalence of probable anxiety and depression among the respondents. The prevalence of probable anxiety was found to be 32.8% among the respondents with a mean HADS sub-scale score for anxiety of 9.8 (SD=2.09). In terms of probable depression, 27.8% of the respondents were found to be affected, and the mean HADS sub-scale score for depression was 10.0 (SD=1.84). There were 40 (20.2%) respondents who had both probable anxiety and depression.

**Table 3.** Prevalence of probable anxiety and depression among caregivers (N=198).

Types of probable disease disorder	n(%)
<i>Anxiety</i>	65 (32.8)
Male	91 (46)
Female	107 (54)
<i>Depression</i>	55 (27.8)
Male	32 (35.2)
Female	23 (21.5)
<i>Normal</i>	118 (59.6)

Age was found to be a protective factor. With every unit increase in age, the odds of probable anxiety were 0.97 (95% CI= 0.953 - 0.996). Caregivers who perceived that the patient under their care was dependent on them had a higher chance of being diagnosed with probable anxiety (OR=2.27, 95% CI= 1.087 - 4.719). Similarly, caregivers who reported caregiving as an economic burden were more likely to be anxious (OR= 2.70, 95% CI= 1.256 - 5.803) (see **Table 4**).

**Table 4.** Factors associated with anxiety (N=198).

Variable	Crude OR	Adjusted OR (95% CI)	B	Wald	df	P value <sup>1</sup>
Age	0.97	0.97 (0.953, 0.996)	-0.028	5.02	1	0.025
<i>Caregiver thinks patient is independent</i>						
Yes	1.00					
No	2.69	2.27(1.087,4.719)	0.818	5.765	1	0.029
<i>Caregiver thinks caregiving is economic burden</i>						
Yes	3.03	2.70 (1.256, 5.803)	0.993	6.468	1	0.011
No	1.00					

df= degrees of freedom, CI= Confidence Interval, OR= Odds Ratio, 1Multiple Logistic Regression (no multicollinearity, assumptions were all met), Receiver Operating Characteristic = 0.685, Overall percentage classification = 91.0%, Hosmer and Lameshow test p-value = 0.089.

Male caregivers were two times more likely to be diagnosed with depression compared to females (OR= 2.21, 95% CI= 1.143 - 4.262). Caregivers who reported that the patient was dependent were 2.53 times more likely to be diagnosed with depression (95% CI= 1.203 - 5.337), while caregivers who did not know how to release stress were 2.48 times more likely to be depressed (95% CI= 1.030 - 5.973) (see **Table 5**).

**Table 5.** Factors associated with depression (N=198).

Variable	Crude OR	Adjusted OR (95% CI)	B	Wald	df	P value <sup>1</sup>
<i>Gender</i>						
Female	1.00					
Male	1.98	2.21 (1.143, 4.262)	0.792	5.558	1	0.018
<i>Thinks patient is independent</i>						
Yes	1.00					
No	2.53	2.53 (1.203, 5.337)	0.930	5.989	1	0.014
<i>Caregiver knows way of stress release</i>						
Yes	1.00					
No	2.38	2.48 (1.030, 5.973)	0.909	4.108	1	0.043

df= degree of freedom, CI= Confidence Interval, OR= Odds Ratio, 1Multiple Logistic Regression (no multicollinearity, assumptions were all met), Receiver Operating Characteristic = 0.648, Overall percentage classification = 94.4%, Hosmer and Lameshow test p-value = 0.746.

### Discussion

Caregiving is a life-changing event that involves added responsibilities, financial burdens, adjustments in terms of time management and changes in the caregivers' social lifestyle, among others. The objective of this study was to study the socioeconomic, individual and environment factors that were associated with mental health status (anxiety and depression) among caregivers of psychiatric patients. Several factors were found to be important and may be of interest to healthcare professionals.

In this study, the finding that there were higher prevalence rates of probable anxiety and depression compared to the general population were congruent with a previous study.<sup>8</sup> These findings can be due to the high sensitivity

and specificity of the HADS screening tool. However, our reported figure is low compared to another previous local study that used HADS and reported the prevalence rates of probable anxiety and depression to be 48.6% and 29.4%, respectively.<sup>8</sup> The differences may be explained by the different type of patients (cancer) that the caregivers in that study were caring for. The significant prevalence rates of probable anxiety and depression among caregivers warrants a proper diagnosis. More effort should be directed at identifying at-risk caregivers as early as possible so that early preventive steps can be formulated and to ensure that lesser cases are missed.

Unamendable factors such as age, gender, ethnicity, and so forth play important roles in the disease diagnosis. Consistent with

many previous studies, female respondents were the majority in this study.<sup>11</sup> However, the ages of the caregivers were younger than expected. Caregivers gained experience and enjoyed personal growth by learning on the job caring for their patients. Lack of experience in providing aid in the activities of daily living may be a reason why males are deterred from being a primary caregiver. In addition, a huge portion of time is spent on managing patients, which, coupled with the need to manage their own disabilities or chronic diseases, may take a toll on the mental health of the caregivers themselves.<sup>12</sup> However, this was not found to be significant in the current study. Although the types of disabilities or diseases that a patient has may impact the health of their caregivers, this topic was not addressed as one of the main focuses of the current research.

Caregiving affects both the mental and physical health of the caregivers. It was initially thought that the older caregivers would experience more stress and be at higher risk of developing mental illnesses, as they belong to the group commonly afflicted with poorer physical functionality and comorbidities. However, this study showed otherwise. The possible explanation for this finding is that aging moulds psychological immunity to stressful experiences, thereby reducing emotional responsiveness while exerting an increased capability to control emotion that could only come with age.<sup>20</sup>

The current study also highlighted the fact that males have a higher preponderance towards depressive disorders.<sup>10,12</sup> Male caregivers in this study were found to be twice as likely to have depression. Males are usually breadwinners with less exposure to caregiving, thus caregiving can become a source of stress, leading to depression. Female caregivers are relationship oriented and are more likely to share their problems with others.<sup>13</sup> Hence, finding more undiagnosed males with depression is to be expected, as they are less expressive in their feelings and are less likely to seek outside help.

Anxiety and depression can co-exist. Caregiving can be a task that affects caregivers in multiple ways. At one end of the spectrum, the caregiver may feel happy and grateful for being given the chance to help the patient, while, at the other end, they may feel sad and sorry or even fear for the patient under their care. The changes in the effect on the caregiver may occur abruptly

and a few times a day. An individual who does not know how to deal with stress is prone to affective disorders.<sup>13</sup> When caregivers become overloaded with stress, they succumb to illness. Although income, employment status and education level were not found to be significant in the current study, caregivers who perceived caregiving as an economic burden tend to be more anxious. Caregiving causes loss in family savings and income. The logistical issues alone are costly, especially in Sarawak, where the geographical situation poses a great challenge. Caregivers may find caregiving expensive and unaffordable and themselves having to forego necessities in order to cope with caregiving expenses.

Mental illness is perceived of and expressed differently according to one's cultural background and ethnicity.<sup>2</sup> There was a difference in the susceptibility to depression and anxiety among different ethnic and racial groups according to the literature.<sup>21-22</sup> However, the current study did not establish relationships between ethnic and racial factors and mental illness, as the population in the study was small and generally homogenous in terms of having lifestyles that have done away with many traditional beliefs. The caregivers received at least a formal primary education and were living in an urban setting with access to telecommunication and media hubs. Despite this, further research is needed in this area.

This study suggested there was a positive correlation between a caregiver's depression and their perception of their patient as being dependent. This single common factor was associated with both probable anxiety and depression in the current study. Caregivers seek support from friends and families, the doctor's office and support groups. When they fail to find support, they may fall into despair. In addition to moral support, knowledge inputs from these sources help caregivers to offset issues arising from patients' dependencies, without which, they might have problems coping. In addition, a lack of knowledge and unclear expectations in terms of the outcomes for the patient may place a caregiver in a state of distrust, thus not allowing others who might be more capable to care for the patient.

Although having a supportive environment was not found to be a significant independent variable, local mental health groups



or associations should not neglect the psychological needs of caregivers.

We acknowledge that the difference in anxiety and depression among caregivers for patients with different diseases was not considered and that culturally-sensitive research pertaining to belief systems within the local context was not done, and that no cause and effect relationships could be established in this study.

### Conclusions

The prevalence of anxiety and depression among caregivers of psychiatric patients is high. The age factor and perception of caregiving as an economic burden are crucial factors in predicting anxiety, while being a male caregiver who is also unequipped to cope with stress was important in the development of depression. The perception of the patient as being dependent was a common denominator for the development of both anxiety and depression. The HADS can serve as an alternative screening tool for anxiety and depression among caregivers. Healthcare worker knowledge, training of staff and regular screening are vital for

the detection of hidden cases. Healthcare professionals must be aware that caregivers for patients suffering from other diseases are also at risk. Culturally sensitive research should be undertaken in the future, as there are more than 20 different ethnicities in Sarawak. More pragmatic data is needed to delineate the relationship between income and risk to the mental health of a caregiver. Due to the nature of the study, generalizations can only be made to similar settings.

### Competing Interest

This study did not receive any funding support. The authors declare that they have no competing interests.

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### How does this paper make a difference to general practice?

It serves as a baseline study of the prevalence rates of anxiety and depression among caregivers of psychiatric patients and their associated factors in a local context.

1. Offers the alternative HADS screening tool instead of the DASS tool currently used.
2. Results can be compared with those for caregivers of patients with other diseases.
3. Highlights the possibility of the emergence of new burden of health issue among the caregivers, as psychiatric patients are now treated in the community.
4. Provides knowledge on the current status in the studied region, providing a guide for the public health specialist to use to plan programming accordingly.

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