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Original article

Anxiety in caregivers of palliative care patients

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Background: Palliative care service undoubtedly aims at quality of life of both the patients and their family members. Caring for the ill can bring about mental burden to the caregivers; but this is understudied in Thai literature.

Objective: This study aimed to explore the anxiety state and associated factors in caregivers of palliative patients, particularly in urban setting as Bangkok.

Methods: We recruited 93 caregivers of inpatients consulted to the Palliative Care Unit of King Chulalongkorn Memorial Hospital. The instruments used include Edmonton Symptom Assessment System (ESAS) - Thai version and The State - Trait Anxiety Inventory (STAI Form). Multiple linear Regression Analysis was used to examine the associated factors of anxiety among family caregivers.

Results: Multiple regression analysis found that caregiver's age ($P = 0.04$), caregiver's relationship to the patient ($P = 0.01$), and caregiver's STAI trait score ($P = 0.1$) had significant association with the caregiver's STAI state score, with effect size (f^2) of 0.04 (small), 0.03 (small), and 0.21 (medium)Á respectively. In subgroup analysis of relative – only family caregiver, multivariate analysis found the following factors caregiver's age ($P = 0.02$), caregiver's STAI trait score ($P = 0.0$), patient's gender ($P = 0.046$) reached significant association with the caregiver's STAI state score.

Conclusion: Certain demographic factors (caregiver's age, degree of relation, and trait anxiety) associated with caregiver's anxiety. However, ESAS, the rating for perceived symptom severity, did not show significant association.

Keywords: Anxiety, family caregivers, palliative.

The term 'palliative care' comprise bio-psycho-social-spiritual approach toward patients with life-threatening illnesses and their families in order to improve their quality of life.(1, 2)

Terminal illnesses affect all age groups. Prevalent amongst elderly are cardiovascular disease, cancer, obstructive lung disease, HIV, and diabetes; whereas congenital malformations, protein malnutrition, encephalitis, HIV, and cardiovascular disorder affects the younger group. The need for palliative care grows as number of noninfectious and cancerous terminal illnesses patients along with elderly population size.(3) Being an elderly society, cancer is one of the leading causes of death in Thailand. The need for specialized care for terminal cancer patients has never been more relevant (now reflected in national hospital accreditation.(4) Myriads of cancer symptoms, physical and psychological, interfere with daily functioning, indirectly burdening their caregivers.(5) It is not uncommon for caregivers in this sense, non-medical professionals (to double as other roles), especially when the caregiver is the patient's family member. They may perform house chores, raise children, transport, or even engage in 9 - 5 jobs. As for caring role, they may be tasked with feeding, hygiene, giving psychological support, or even exercising medical power of attorney.(6) They are vulnerable to physical and psychological distress.(7) Stress is more prevalent among caregivers than those of general population (41.0 – 62.0% vs. 19.0%). They also have high rates of anxiety and depression.(8)

Psychological stress of caregiver was correlated with disability of those being cared for.(9) Without mental wellbeing, one cannot hope to function properly (caring for the ill in this case). Whether caregivers are doing well mentally is therefore a relevant question in palliative care. Anxiety, a fundamental negative emotion, is yet understudied among Thai palliative caregivers. We therefore aim to explore demographic factors and perceived symptom severity associated with caregiver's anxiety in palliative care patients.

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Materials and methods

Sample collections

This is a cross sectional study. Subjects were caregivers to palliative care patients from medical, obstetrics-gynecological, ear-nose-throat, and radiotherapy wards. The inclusion criteria include: 1) being a caregiver (in family context, relative or not) of palliative care patient of Cheewabhibaln Center's inpatient department roster for whom they provide care by feeding, ambulating, assisting in nursing care or physical therapy and so on; 2) age over 18 year-old; and, 3) the caregiver (and the patient, where possible) consent to the research procedures. In case that there were more than one caregivers, data were collected from the one that were present at the admission. We recruited target sample size of 93 subjects. Our study has been approved by the Institutional Review Board of the Faculty of Medicine, Chulalongkorn University (COA No. 213/ 2018).

Measurements

Data were collected through self-rated questionnaires including: 1) caregiver's demographic data, rated by the caregiver; 2) palliative patient's demographic data, rated by their respective caregiver; 3) Edmonton Symptom Assessment System (ESAS)-Thai version, developed by Jaturapatporn D, *et al.* a self-reported questionnaire assessing perceived symptom severity in varied domains with 10 items (see later) rated on a 11 - point scale and higher being more severe. The Cronbach's Alpha coefficient in the previous study was 0.80 stability was high ($r = 0.8$). The measure was also tested for concurrent validity.(10)

We follow the measure's instruction that, where possible, the rating is obtained from the patient. In other cases (e.g. patient is unconscious or delirious) caregiver gives the rating in patient's stead; and, 4) The State - Trait Anxiety Inventory (STAI Form) developed by Spielberger C, *et al.* (11) Thai version developed by Kotchabhakdi N, *et al.* (12) STAI Form is a two - part, self - reported questionnaire screening for state (part 1) and trait (part 2) anxiety. Higher scores indicating a greater severity of anxiety. The Cronbach's Alpha coefficient of the STAI form Thai version was 0.87.(13) Score from the first part (state anxiety) is the primary outcome of our study. The data are rated by the caregivers.

Statistical analysis

Data were expressed as mean ± standard deviation (SD) and analyzed with Statistical Package for Social Science (SPSS) version 22. Univariate analysis was performed using F-test family statistics and bivariate correlations (Pearson correlation or Spearman's rho, depending on distribution). Factors with potentials for association were then included in multivariate analysis using multiple linear regression. Missing data were replaced with means. Post-hoc analysis for regression model's statistical power were carried out using G*Power (University of Dusseldorf) version 3.1.9.4. P – value < 0.05 was considered as significant difference.

Results

Among the 93 subjects, most of them were female (77.4%), unemployed (28.0%), without debt (86.0%) and without underlying disease (54.8%). Their averaged age was 51.9 years, with averaged education years of 12.5 years; their averaged hour of care was 11.9 hours a day; their averaged income was around 30,000 baht, and their averaged STAI trait anxiety score was 43.1 points. Details are shown in Table 1.

The majority of patients were female (59.1%) married (61.3%) Buddhist (94.6%) with diagnosis of cancer (72.0%). Their age averaged 60 years, with duration of illness averaged 29.5 months. Their average ESAS score ranged from 2.1 to 6.38, lowest being ESAS3 (nausea) and highest being ESAS2 (fatigue). Details are shown in Table 2.

Bivariate correlation was undertaken to explore potential association between independent continuous data and primary outcome (STAI state score) as shown in Table 3. Caregiver's age and patient's age showed potential negative correlation; while caregiver's education year, ESAS5, and STAI trait score show potential positive correlation.

Comparison of the means using f-test statistics was undertaken to explore potential association between independent categorical data and primary outcome (STAI state score) as shown in Table 4. Caregiver's occupation caregiver's debt status, caregiver's relationship to the patient showed potential association.

The aforementioned factors with potential association with primary outcome were then entered in multivariate analysis using multiple regression. Final regression model maintains caregiver's age, caregiver's relationship to the patient, and caregiver's STAI trait score having significant association with the primary outcome (Table 5). Effect sizes or

f^2, calculated from R^2 changes of adjusted model of caregiver's age, caregiver's STAI trait, and caregiver's relation to patient were 0.03, 0.27, and 0.10, indicating small, medium, and small effect size respectively. We performed post - hoc analysis on statistical power using G*Power. Our model had statistical power ($1 - \beta$) to detect medium effect size of 0.72.

Subgroup analysis of relative-only family caregiver found potential association of the following factors: 1) caregiver's age; 2) caregiver's STAI score; 3) caregiver's relation; 4) caregiver's balance status; and, 5) patient's female gender. The first, second, and fifth factor reached significance in multivariate analysis as shown in Table 6.

Table 1. Socio-demographic and STAI score of the participants (n = 93).

Characteristics	**Mean ± SD or n (%)**
Sex	
Male	21 (22.6)
Female	72 (77.4)
Age (years)	51.9 ± 15.2
Marital status	
Married	57 (61.1)
Separated	9 (9.7)
Divorced/Widowed/other	3 (3.2)
Single	24 (25.8)
Educational level (years)	12.5 ± 3.6
Occupation	
Unemployed	26 (28.0)
Private sector	10 (10.8)
Laborer	19 (20.4)
Government	18 (19.4)
Business owner	20 (21.5)
Personal income (baht/month)	31,792 ± 49,796
Adequacy of income	
No debt	80 (86.0)
Has debt	13 (14.0)
Underlying disease	
Absent	51 (54.8)
Present	41 (44.0)
Relationship with patient	
Close relatives (spouse, parent, offsprings)	54 (58.1)
Distant relatives	28 (30.1)
Nonrelative	11 (11.8)
Religion	
Buddhism	92 (98.9)
Islam	1 (1.1)
Caring hours per day	11.9 ± 7.6
Trait anxiety from STAI	43.1 ± 8.8
State anxiety from STAI	54.1 ± 11.0

Missing percentage in any variable indicates missing data

Table 2. Socio - demographic of the palliative patient (n = 93).

Characteristics	Mean ± SD or n (%)
Sex	
Male	38 (40.9)
Female	55 (59.1)
Age (years)	60.0 ± 16.9
Marital status	
Married	57 (61.3)
Separated	9 (9.7)
Divorced/Widowed/other	9 (9.7)
Single	18 (19.4)
Educational level (years)	12.8 ± 3.9
Religion	
Buddhism	88 (94.6)
Christianity	3 (3.2)
Islam	1 (1.1)
Diagnosis	
Cancer	67 (72.0)
Non-cancer	23 (24.7)
Duration of diagnosis (months)	29.5 ± 39.6
ESAS1 pain	4.9 ± 3.3
ESAS2 fatigue	6.4 ± 2.6
ESAS3 nausea	2.1 ± 3.2
ESAS4 depression	4.0 ± 3.1
ESAS5 anxious	4.7 ± 3.2
ESAS6 drowsiness	5.8 ± 3.3
ESAS7 anorexia	4.5 ± 3.8
ESAS8 wellbeing	6.0 ± 2.9
ESAS9 dyspnea	5.5 ± 3.0

Missing percentage in any variable indicates missing data

Table 3. Bivariate correlation between STAI state score and the following factors.

Variables	Correlation coefficient	*P* - value
Caregiver age	- 0.3[a]	0.1
Caregiver education year	0.2[a]	0.1
Caregiver income	- 0.0[b]	0.7
Caregiver care hours	0.1[a]	0.6
Patient age	- 0.2[a]	0.0
Patient education years	- 0.2[a]	0.2
Patient duration of diagnosis (month)	0.1[b]	0.6
ESAS1 pain	- 0.1[a]	0.6
ESAS2 fatigue	0.1[a]	0.5
ESAS3 nausea	0.0[a]	1.0
ESAS4 depression	0.1[a]	0.3
ESAS5 anxious	0.2[a]	0.1
ESAS6 drowsiness	0.1[a]	0.2
ESAS7 anorexia	0.2[a]	0.2
ESAS8 wellbeing	0.2[a]	0.2
ESAS9 dyspnea	0.2[a]	0.2
ESAS10 others	- 0.1[a]	0.7
Trait anxiety	0.5[a]	0.1

a: Pearson correlation

b: Spearman's rho

Table 4. Comparison of the means of STAI state score.

Factor	Mean ± SD	*P*-value
Caregiver gender		
Male	54.1 ± 10.2	0.4
Female	53.8 ± 11.2	
Caregiver status		
Married	54.2 ± 10.8	0.33
Separate	56.2 ± 12.3	
Widowed	63.7 ± 11.9	
Single	52.0 ± 10.7	
Caregiver occupation		
None	54.7 ± 9.7	0.01
Private employee	62.0 ± 10.7	
Labor	50.6 ± 10.1	
Government	54.7 ± 9.6	
Own business	52.2 ± 13.4	
Caregiver financial		
No debt	53.3 ± 10.7	0.08
Has debt	59.1 ± 12.0	
Caregiver underlying disease		
Present	53.6 ± 11.9	0.45
Absent	54.8 ± 10.2	
Caregiver relationship		
Close relative	56.8 ± 9.4	0.01
Distant relative	51.6 ± 12.0	
Non-relative	47.6 ± 312.0	
Caregiver religion		
Buddhism	54.1 ± 11.1	0.87
Islam	56.0 ± 0.0	
Patient gender		
Male	55.9 ± 11.2	0.19
Female	52.9 ± 10.5	
Patient status		
Married	55.7 ± 9.4	0.20
Separate	53.0 ± 12.6	
Widowed	47.4 ± 12.4	
Single	53.2 ± 13.6	
Patient religion		
Buddhism	54.3 ± 11.2	0.53
Christianity	47.0 ± 2.7	
Islam	54.1 ± 11.1	
Patient diagnosis		
Cancer	54.7 ± 10.7	0.18
Non cancer	51.1 ± 11.8	

Table 5. Association with the primary outcome.

Model	Unstandardized Coefficients b	Unstandardized Coefficients Standard Error	Standardized Coefficients Beta	*t*	*P* - value
Constant	43.7	7.1	0.0	6.1	0.01
Trait anxiety	0.5	0.1	0.4	4.8	0.01
Caregiver's degree of relation to the patient	- 3.8	1.4	- 0.2	- 2.8	0.01
Caregiver age	- 0.1	0.1	- 0.2	- 2.1	0.04

R-squared of the model = 0.335

Table 6. Association with the primary outcome (related only family caregiver).

Model	Unstandardized Coefficients b	Unstandardized Coefficients Standard Error	Standardized Coefficients Beta	*t*	*P* - value
Constant	48.8	8.1	6.0	0.01	
Trait anxiety	0.5	0.1	0.5	4.8	0.01
Caregiver age	- 0.2	0.1	- 0.3	- 3.2	0.002
Female Patient	- 4.1	2.0	- 0.2	- 2.0	0.046

R-squared of the model = 0.378

Discussion

We found that caregivers have elevated anxiety score, with means around 54 (in mild to moderate range). This is in accord with the findings of Grov EK, *et al.*(14) that caregivers have anxiety levels higher than the general population.

Our result indicated that certain demographic factors (caregiver's age, degree of relation, and trait anxiety) were associated with caregiver's anxiety state. However, ESAS, the rating for perceived symptom severity, did not show significant association with raw correlation being weak at best. This is different from Dumont S, *et al.*(9) that caregiver's psychological distress rose as patient became more dependent from disease progression. Possible explanation could be that ESAS, being subjective rating, may not correctly identify the need for assistance from the caregiver which would increase their burden and thus psychological distress.

Our average anxiety score was, however, higher than a previous study using the same measure in different language by Ugalde A, *et al.*(15) which found the score of 45. Their study, similar to us, found that duration of illness did not predict anxiety score. They did not find significance association for spousal caregiver, which is different from our findings. Their study also found caregiver's gender to be associated with anxiety, which is not the case in our findings. They have also looked into self - efficacy ratings of caregivers and found an item to be predictive. We did not control these factors and this might contribute to difference in our findings. Of note, our patients consisted entirely of IPD patients while Ugalde A, *et al.*(15) was conducted in OPD settings. Viewed in cross - section, IPD caregivers assume less physical responsibility of the patients than OPD caregivers as part of the burdens are shared by nursing staff. Those that have been burdened by the task can either be relieved by the admission, or on the other hand may be troubled by the increasing severity of the disease of the cared. In cases the patients were admitted from the beginning of palliative care, such shift of responsibility and resultant effect on anxiety would not be present. They, however, may still develop anxiety from the cared having illness so severe that admission is warranted from the beginning of palliative care.

Caregiver's age and degree of relation predicting their anxiety is concordant with Nipp RD, *et al.*(16)

among caregivers of lung and gastrointestinal cancers. We, however, did not find significant association with caregiver's religion as our subjects' variance were too low.

Degree of relation predicting anxiety is also found in Mystakidou K, *et al.*(17) But our study differed in that our caregiver's gender did not predict anxiety as in their study. We also did not look into caregiver's self - efficacy, which was a significant predictor in their study. This limitation in design may have contributed to confounder in our study.

Grunfield E, *et al.*(8) looked into caregiver's anxiety status and found that predictors were caregiver's burden (especially financial), patient's anxiety, and patient's physical functioning. Our result found tendency toward significance from caregiver's financial balance but the factor failed to reach significance in multivariate analysis. Grunfield E, *et al.*(8) also found that burden rose at time progress but our study failed to detect significant association between duration from diagnosis and caregiver's anxiety. We have not directly looked into patient's physical functioning or anxiety, but generally most of our patients had progressive illnesses as more than half were unable to rate ESAS for themselves. Of note, our study looked into broader category of palliative patients while Grunfield E, *et al.*(8) studied palliative breast cancer patients.

Harding R, *et al.*(18) also studied anxiety of the caregiver and found that patient's psychological status predicted caregiver's anxiety while patient's pain predicted caregiver's psychological morbidity in other domains. Our study looked into patient's symptoms through ESAS (item 1) but there was no significant tendency of association with anxiety. In line with Harding R, *et al.*(18), the item may be more correlated with other caregiver's psychological morbidity. As design limitation, we have not directly looked into patient's psychological status. We argue that our respective patients may be of greater severity. As we previously mentioned, more than half of our patients were unable to rate ESAS for themselves.

A person's trait anxiety predicting him/herself developing anxiety is a statement that generally makes sense and we have not found literature describing this finding in the context of caregiving. The effect size was medium. Also, the more closely you are related to the ills, the more you become anxious with their illnesses is a conclusion much concordant with previous studies. Caregiver's age, however, remains a mixed finding. If these were to be replicated in the Thai context, we may be able to develop screening measures and interventions targeting caregivers at risk for anxiety. For example, at-risk demographic data may be identified and these particular groups of caregivers may be offered targeted psychological interventions. Such practice would improve quality of life of both the caregivers and, the patients.

Our study is the first to evaluate factors affecting palliative caregiver anxiety in Thai literature. Although we have reached the target size of samples, our study still has limitations. Our regression model was underpowered to detect factor with effect size below medium as we initially expected. Nevertheless, two factors with small effect sizes managed to reach statistical significance, portending the possible false negatives on other factors of small effect size. In addition, we conducted the study in the inpatient settings of King Chulalongkorn Memorial Hospital, which is a tertiary care hospital and a medical school. This could have affected respective case being more severe and may not properly represent all palliative cases.

Other limitation lies in missing data of ESAS7 (appetite) and ESAS10 (other self - defined symptoms). The first had roughly half missing data as our patients, being possibly more severe than other studies, were either unconscious, under NPO, under nasogastric feeding, or under parenteral nutrition. The latter were too heterogeneous to be of any value. Since our design is cross – sectional and no causality can be concluded. Further study may consider looking into larger sample from broader settings so as the result becomes more representative. Instruments that directly measure patient's dependency and caregiver's perceived self – efficacy should also be included in future researches.

Conclusion

Certain demographic factors (caregiver's age, degree of relation, and trait anxiety) may be associated with caregiver's anxiety state. None of ESAS items measuring perceived symptom severity correlated with caregiver's anxiety. These findings need to be replicated before conclusion can be drawn for Thai palliative family caregiver's anxiety.

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Conflict of interest

The authors, hereby, declare no conflict of interest.

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