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Original article

Resilience and associated factors of family caregivers of the terminal illness patients at Cheewabhibaln Center, King Chulalongkorn Memorial Hospital

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Background: Family caregivers play an important role to provide support and care for terminal illness patients by spending their time responding to the patients' needs. Receiving this role can cause them to be stressful and anxious. Therefore, it is essential for them to have resilience so that they are able to overcome potentially all burdens.
Objectives: The present study aimed to examine resilience and associated factors of family caregivers of the terminal illness patients at Cheewabhibaln Center, King Chulalongkorn Memorial Hospital.
Methods: This descriptive study was conducted in 150 family caregivers. The sample group was recruited through the purposive sampling method from both male and female family caregivers who had been taking care of the terminal illness patients for one continuous month. Moreover, the subjects completed eight questionnaires including: 1) Demographic Characteristics Form; 2) Caregiving Data Form; 3) Zarit Caregiver Burden Scale; 4) Conner-Davidson Resilience Scale Questionnaire; 5) The Revised version of Thai Rosenberg Self-Esteem Scale; 6) Thai Hospital Anxiety and Depression Scale (Thai HADS); 7) Social Support Questionnaire; and, 8) Family Relationship and Function Questionnaire
Results: The average scores of resilience in family caregivers of the terminal illness patients were 69.7 ± 13.8 which lower than the average scores of the population. Factors associated with moderate-to-high level of resilience included no use of sedatives/hypnotics ($P < 0.05$), no anxiety ($P < 0.05$), no depression ($P < 0.05$), moderate-to-high level of overall social support scale ($P < 0.05$), with moderate-to-high level of each dimension of social support scale which consisted of; emotional support ($P < 0.01$), informational support ($P < 0.01$) and tangible support ($P < 0.05$). Furthermore, it was found that the predictors of moderate-to-high level of resilience were no use of sedatives/hypnotics ($P < 0.05$), and moderate-to-high level of social support ($P < 0.01$).
Conclusion: Family caregivers of the terminal illness patients had lower level of resilience than the general population. The associated factors and predictors of moderate-to-high level of resilience were no use of sedatives/hypnotics and moderate-to-high level of social support. Therefore, in order to promote resilience in the family caregivers, supporting their mental health and providing good social support in every dimension especially the informational support would be crucial to the family caregivers.

Keywords: Resilience, family caregivers, terminal illness patients.

A terminal illness patient is someone who cannot be cured from the disease with the purpose of maintaining the conditions and improving the quality of life until their last breath. There are 40 million terminal illness patients[1] globally battling with cardiovascular disease, respiratory disease, AIDS, etc. Likewise, it is reported that such diseases are the primary causes of death in Thailand[2] which the terminal illness patients have to experience distressing physical symptoms, such as body pain, fatigue, nausea, loss of appetite, confusion, rambling, etc. In addition, these patients undergo unpleasant emotions, for example separation anxiety, unsettlement, worrying about their own family members, etc. These symptoms interrupt their daily routine so greatly that

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the assistance from family members are required. In line with the caregivers in general[3], family caregivers play a crucial role in the patients' lives as they have to assist the patients according to their needs, observe the symptoms, help relieve the pain, be the point of contact and make important decisions for the patients. With additional duties, the family caregivers may develop stress from having to adjust their work or personal schedules which cause them to have limited personal times, not being able to come out of the house and feel exhausted from waking up early to take care of the patients.[4] As the family caregivers have continuously practiced their new routine over time, it would inevitably bring about stress and tensions to them. Hence, it is necessary for the family caregivers to have resilience because they have to carry the burden of caregiving and potentially experience the loss of their family members which is considered a family crisis. If they could not cope with such experiences, it may result in reintegration with loss and not being able to function as before.[5]

Resilience is the ability of an individual to cope with disruptions and return to the pre-crisis status amidst the adversity which would equip family caregivers to live their lives after a family crisis. As a result, Cheewabhibaln Center of King Chulalongkorn Memorial Hospital exists to assist family caregivers of the terminal illness patients. Moreover, it also serves as a support system to improve the quality of life of the terminal illness patients during their final moments and their family caregivers to accept and cope with the potential loss.

Researchers have found that resilience in family caregivers of the terminal illness patients are low**.** According to Hwang IC, *et al.* [6] the average score of resilience in family caregivers of terminal cancer patients were low. Furthermore, Ong HL, *et al.* [7] discovered that resilience's average score of family caregivers of elderly patients with physical or mental illness were also low. However, the studies on resilience of family caregivers of the terminal illness patients in Thailand are rather limited.

Therefore, this current research aims to examine resilience and associated factors of the family caregivers of the terminal illness patients with the purpose to help the family caregivers and the terminal illness patients to adapt better and improve their quality of lives.

Materials and methods

This descriptive study was conducted in 150 family caregivers who were sent to–Cheewabhibaln Center, King Chulalongkorn Memorial Hospital for consulting. The data collecting period was from September 2019 to January 2020. The sample group was recruited through the purposive sampling method with the inclusion criteria including; family caregivers of the terminal illness patients who were 18 years old or more and spent time with the patients 6 hours a day for 1 continuous month. This present study was considered and approved by the Research Ethics Review Committee for Research Involving Human Research Participants, Faculty of Medicine, Chulalongkorn University **(**IRB no. 274/62**)**.

The subjects were explained the objectives of the study and voluntarily participated in the study by answering all the instruments as follows: 1) Demographic Characteristics Form; 2) Caregiving Data Form; 3) Zarit Caregiver Burden Scale; 4) Conner-Davidson Resilience Scale Questionnaire **(**CD-RISE**)**; 5**)** The Revised version of Thai Rosenberg Self-Esteem Scale: Revised Thai RSES; 6**)** Thai Hospital Anxiety and Depression Scale (Thai HADS**)**; 7**)** Social Support Questionnaire; and, 8**)** Family Relationship and Function Questionnaire. Details of the instruments are as follows:

Zarit Caregiver Burden Scale was developed by Toonsiri C. using the theory of Zarit SH. and Zarit JM. The instrument was used to evaluate the burden of caregivers through 22 items with the range scores of 0 - 88. The interpretation of the scores was divided into 4 parts including: 1) No burden (lower than 21 point); 2) Mild burden (21 – 40 points); 3) Moderate burden (41- 60 points); and, 4) Severe burden (more than 61 points). The internal consistency – Cronbach's alpha of the instrument = 0.92.

Conner-Davidson Resilience Scale Questionnaire was developed by Khongphaisansophon A.[8] according to the theory invented by Conner and Davidson.

There were 25 questions with the total scores range from 0 – 100 where a higher total score indicating greater resilience. The interpretation of the scores was divided into 3 levels including; 1) Low means an individual with lower scores than the mean-standard deviation (SD); 2) Moderate means an individual with the scores in between the mean ± SD; and, 3) High means an individual with the scores higher than the mean ± SD. The internal

consistency – Cronbach's alpha of the inventory = 0.89.

The revised version of Thai Rosenberg Self-Esteem Scale was developed by Wongpakaran T. which influenced by Morris Rosenberg' principle. The instrument consisted of 10 items with the total scores in the range of 10 – 40 points. The scoring of self-esteem was divided into 3 levels including: 1) Low (lower than 26 points); 2) Moderate (26 – 32 points); and, 3) High (more than 32 points). The internal consistency – Cronbach's alpha of the instrument = 0.86.

Thai Hospital Anxiety and Depression Scale was developed by Nilchaikovit T, Lortrakul M, and Phisansuthideth U. which was translated into Thai from The hospital anxiety and depression scale by Zigmond AS. and Snaith RP. (1983). The inventory consisted of 14 questions which separated into 7 items for anxiety and others for depression. The interpretation of the scores were: 1) No anxiety/depression 0 – 7 points); 2) Anxiety/Depressive symptoms (doubtful cases) (8 – 10 points); and, 3) Anxiety/Depressive disorder (11 points or more). The internal consistency – Cronbach's alpha of the anxiety inventory = 0.86 and of the depression inventory = 0.83.

Social Support Questionnaire was used to determine social support level which was developed by Lueboonthavatchai O. and Lueboonthavatchai P. based on Schaefer's concept. The measurement composed of 3 dimensions of social support which were namely: 1) Emotional support (7 items with the Cronbacch alpha coefficient equals to 0.91); 2) Informational support (4 items with the Cronbacch alpha coefficient equals to 0.88); and, 3) Tangible support (5 items with the Cronbacch alpha coefficient equals to 0.87). The score's interpretation was divided into 3 levels including: 1) Low means an individual with lower scores than the mean-SD; 2) Moderate means an individual with the scores in between the mean ± SD; and, 3) High means an individual with the scores higher than the mean ± SD. The internal consistency – Cronbach's alpha of the instrument = 0.89.

Family Relationship and Function Questionnaire was invented by Lueboonthavatchai P. through his literature review. The inventory consisted of 7 items with the total score from 0 – 35 points. The scores were divided in 3 different ranges for family relationship and function including high, moderate and low respectively. The internal consistency – Cronbach's alpha of the inventory = 0.93.

Statistical analysis

In addition, the data were analyzed through the statistic computer program SPSS version 22 in order to find the resilience in family caregivers of the terminal illness patients which presented in frequency and percentage. Moreover, Chi-square test was used to find the associated factors as well as logistic regression was used to find the predictors of the resilience in family caregivers of the terminal illness patients with a statistically significant at P - value < 0.05.

Results

The total numbers of the family caregivers of the terminal illness patients were 150 people, most of the subjects were female (75.3%) with average age of 47 years old. Furthermore, the majority of the sample group were married (56.0%), finished undergraduate degree (46.0%), not working (34.0%) with monthly income lower than 20,000 THB/month which was adequate and able to save up (49.3%). Additionally, most subjects did not have any health conditions (62.0%), no mental illness history (96.7%), no history of smoking, alcohol usage or sedatives/ hypnotics (96.0%, 82.0%, 94.7% respectively). Most terminal illness patients were related to the subjects as parents (43.3%), required less than 1 year of care (54.0%) with chronic diseases (94.7%) (Table 1).

It was found that the average score of resilience of the family caregivers was 69.7 ± 13.8. Most of the family caregivers reported that it was not a burden to take care of the patients (54.7%), had moderate self-esteem (75.3%), did have anxiety (30.7%), did have depression (12.7%), had moderate overall social support and in each social support dimension (emotional, informational, tangible) (64.7%) and had good family relationship and function (66.0%) (Table 2 and 3).

The associated factors with moderate-to-high level of resilience in the family caregivers of the terminal illness patients included no use of sedatives/ hypnotics ($P < 0.05$), anxiety ($P < 0.05$), depression ($P < 0.05$), moderate-to-high level of overall social support ($P < 0.05$), moderate to high level of emotional support ($P < 0.01$), moderate-to-high level of informational support ($P < 0.01$) and moderate-to-high level of tangible support ($P < 0.05$), (Table 4).

The predictors of moderate to high level of resilience included no use of sedatives/ hypnotics ($P < 0.05$), and moderate-to-high level of social support ($P < 0.01$) (Table 5).

Table 1. Demographic characteristics of family caregivers of the terminal illness patients in Cheewabhibaln Center, King Chulalongkorn Memorial Hospital.

Demographic Characteristics	N	%	Demographic Characteristics	N	%
Sex			State enterprise employee	4	2.8
Female	113	75.3	**Average income (THB / month)**		
Male	37	24.7	≤ 20,000	75	50.0
Age (years)			20,001 – 30,000	21	14.0
≤ 30	27	18.0	30,001 or more	54	36.0
31 – 40	26	17.3	Mean = 31,609.53 (37,584.24), min = 0, max = 300,000		
41 – 50	29	19.3	**Physical health conditions**		
51 – 60	34	22.7	No	94	62.7
61 – 70	25	16.7	Yes	56	37.3
70 or over	9	6.0	**Use of sedatives / hypnotics**		
Mean = 47.3 (15.8), min = 18, max = 78			Never	142	94.7
Marital status			Sometimes	7	4.7
Married	84	56.0	Often	1	0.6
Single	50	33.3	**Patient's relation to the caregiver**		
Widowed	9	6.0	Parents	65	43.3
Divorced	7	4.7	Spouse	30	20.0
Highest educational status			Relatives	23	15.3
Elementary school	9	6.1	Children	18	12.0
Middle school	14	9.3	Siblings	14	9.4
High school	10	6.7	**Duration of care giving (year)**		
Vocational certificate	8	5.3	≤ 1	81	54.0
High vocational certificate	8	5.3	> 1 – 2	24	16.0
Undergraduate	69	46.0	2 or more	45	30.0
Postgraduate	32	21.3	Mean = 28 months and 12 days (43 months and 15 days), min = 1 month, max = 20 years		
Occupation			**Characteristics of disease**		
Not working	51	34.0	Chornic disease	142	94.7
Business owner	40	26.7	Acute disease	8	5.3
Company employee	28	18.7			
Government officials	12	8.0			
Laborer	6	4.0			
Others	9	6.0			

Table 2. Resilience and associated factors of family caregivers of the terminal illness patients in Cheewabhibaln Center, King Chulalongkorn Memorial Hospital (n = 150).

Resilience	N	%	Anxiety	N	%
High	25	16.7	Normal	57	38.0
Moderate	102	68.0	Borderline abnormal	47	31.3
Low	23	15.3	Abnormal	46	30.7
Mean = 69.7 (13.8), min = 22, max = 100			Mean = 8.8 (4.0), min = 1, max = 21		
Caregiver's Burden	**N**	**%**	**Depression**	**N**	**%**
No burden	82	54.7	Normal	99	66.0
Mild burde	56	37.3	Borderline abnormal	32	21.3
Moderate burden	11	7.3	Abnormal	19	12.7
Severe burden	1	0.7	Mean =6.6 (3.5), min = 0, max = 19		
Mean = 20.2 (12.9), min = 1, max = 79					

Table 2. (Con) Resilience and associated factors of family caregivers of the terminal illness patients in Cheewabhibaln Center, King Chulalongkorn Memorial Hospital (n = 150).

Self-esteem	**N**	**%**	**Family relationship and function**	**N**	**%**
High	26	17.3	Good	99	66.0
Moderate	113	75.3	Moderate	43	28.7
Low	11	7.4	Not good	8	5.3
Mean = 31.9 (4.0), min = 15, max = 40			Mean = 28.9 (5.3), min = 11, max = 35		

Social support	**High**		**Moderate**		**Low**	
	N	**%**	**N**	**%**	**N**	**%**
Overall social support Mean = 61.9 (10.6), min = 31, max = 80	28	18.7	97	64.7	25	16.6
Emotional support Mean = 28.5 (4.8), min = 10, max = 35	28	18.7	102	68.0	20	13.3
Informational support Mean = 15.6 (2.9), min = 4, max = 20	27	18.0	97	64.7	26	17.3
Tangible support Mean = 17.8 (4.9), min = 5, max = 25	28	18.7	100	66.7	22	14.7

Table 3. The correlations between associated factors and resilience of family caregivers of the terminal illness patients in Cheewabhibaln Center, King Chulalongkorn Memorial Hospital (n = 150).

Demographic	**Characteristics**	**Resilience**				***P*-value**
		Low		**Moderate-to-high**		
		N	**%**	**N**	**%**	
Use of sedatives/ hypnotics	Never	19	13.4	123	86.6	0.020*
	Sometimes to often	4	50.0	4	50.0	
Anxiety	Abnormal	12	26.1	34	73.9	0.015*
	Normal	11	10.6	93	89.4	
Depression	Abnormal	6	31.6	13	68.4	0.035*
	Normal	17	13.0	114	87.0	
Overall social support	Moderate-to-high	13	10.4	112	89.6	0.046*
	Low	10	40.0	15	60.0	
Emotional support	Moderate-to-high	13	10.0	117	90.0	< 0.001**
	Low	15	75.0	5	25.0	
Informational support	Moderate-to-high	11	8.9	113	91.1	< 0.001**
	Low	12	46.2	14	53.8	
Tangible support	Moderate-to-high	16	12.5	112	87.5	0.029*
	Low	7	31.8	15	68.2	

*$P < 0.05$ ** $P < 0.01$

Table 4. The predictors of moderate-to-high level of resilience of family caregivers of the terminal illness patients in Cheewabhibaln Center, King Chulalongkorn Memorial Hospital (n = 150).

Predictors of moderate-to-high level of resilience	**Adjusted OR**	**95% CI of adjusted OR**		***P*-value**
		Lower	**Upper**	
No use of sedatives / hypnotics	6.935	1.248	38.532	0.027*
No anxiety	1.726	0.565	5.276	0.338
No depression	1.036	0.244	4.408	0.962
Moderate-to-high level of social support	5.923	2.043	17.174	0.001**

*$P < 0.05$ ** $P < 0.01$

Discussion

This study found that 150 family caregivers of the terminal illness patients who received counselling at Cheewabhibalm Center had the average scores of resilience equal to 69.7 ± 13.8. Compared to resilience's average scores of the population which were 80.4 ± 12.8, the target group had lower average scores of resilience than the population. Moreover, Hwang IC, *et al*. [6] stated that family caregivers of terminal cancer patients had low level of resilience (scores equal to 62.2 ± 16.3) which had the similar findings as the research of Ong HL, *et al*. [7] They also discovered that the resilience scores of the family caregivers of the elderly patients with physical or mental illness were low (scores equal to 70.8 ± 15.1). The reasons that the resilience of family caregivers were low because the patients required attention both physically and mentally together with the continuation of time that spend caring the patients that last long until the final moments of the patients. Other than that, family caregivers had to be the point of contact and may decide on important decisions for the patients as well. This could result in stress and tensions for the family caregivers which made it difficult for them to adapt to the current situation and cause the decrease of resilience in the family caregivers. This theory was supported by the resilience model of Richardson GE.[5] which stated that when an individual faces a disruption in life, it would affect one's resilience so much that they could not come back to the pre-crisis state and might lose their function as before.

As for the burden of family caregivers, it was found that most subjects did not feel like taking care of the terminal illness patients was a burden (54.7%) which possibly because the majority of them did not work; hence, they had time to fully care for the patients. Furthermore, most subjects reported that they recieved adequate income with some left to save up which could come from their own pension or given by other family members/relatives. This result was supported by the research of Dias R, *et al*.[9] as they also found that the family caregivers who did not have a job but had enough income which lessen the burden for the caregivers. Additionally, Chomchoed O. [4] explanined that in Thai context, family caregivers felt as though they were under the obligation to give back to the family members and ought to do so, therefore, these reasons helped them to cope with the exhaustion from caregiving.

In addition, the result showed that self-esteem of the family caregiving of the terminal illness patients (75.3%) was moderate. Most of them did not have anxiety nor depression (38.6% and 66.0% respectively) which could relate to not feeling that they had a burden on them and received adequate income. According to Lamliangpon P. [10], who found that inadequate income of the family caregivers was a significant predictor for anxiety disorder.

Moreover, the associated factors of moderate-to-high level of resilience included no use of sedatives / hypnotics, anxiety, moderate-to-high level of overall social support, moderate-to-high level of emotional support, moderate-to-high level of informational support and moderate-to-high level of tangible support. As for the family caregivers of the terminal illness patients who did not use of sedatives / hypnotics, it implied that they had the ability to acknowledge their emotions and adapt to the new environment because most people who use of sedatives / hypnotics tend to be stressed, tensed and anxious which brought about the insomenia.

Having no anxiety related to moderate-to-high level of resilience because when there is no tension, one can adjust to a crisis. This was supported by the studies of Manzini CSS, *et al*.[11] and Hwang IC, *et al*.[6] Moreover, several researches proved that moderate-to-high level of overall social support and of each dimension of social support (emotional, informational and tangible) had the positive correlation with resilience.[6,12-14] Social support was considered as a factor that helped an individual undergo disruptions in life which resulted in: 1) the positive emotions, safety and self-confidence of an individual when one acknowledges that s/he is being supported: and, 2) the decrease of stress, tension and anxiety of an individual when one faces adversity which help him/her to better adjust and has resilience.[9]

This current study also found that the predictors of moderate-to-high level of resilience included no use of sedatives/hypnotics and moderate-to-high level of social support. According to the systematic review of Manzini CSS, et al.[11], who stated that the usage of medication and relationship problems of family caregivers affected their resilience.

This research showed that the family caregivers of the terminal illness patients had lower resilience than the population. It also revealed that factors associated with resilience included no use of sedatives/ hypnotics and social support. Consequently, in order to promote resilience in the family caregivers, it is

crucial to support their mental health and providing good social support in every dimension especially the informational support where they are given details about the symptoms and the treatment of the patients. The necessary information provided to the caregivers would help them feel confident and less stress about caregiving. This supported by the study of Hampe SO.[15] Roen I, *et al*.[16] and Suktrakul S.[17] as they discovered that family caregivers needed informational support the most.

Furthermore, this present study collected data from the family caregivers of the terminal illness patients who were sent to Cheewabhibaln Center, King Chulalongkorn Memorial Hospital for consulting. Therefore, this group of subjects could not represent caregiver in general. The future studies may need to consider the characteristics of the target group before referencing. Additionally, this was a descriptive study which only showed the associated factors of resilience; however, it could not indicate the cause of resilience.

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Conflict of interest

The authors, hereby, declare no conflict of interest.

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