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## Original article

# Relationships of stress, anxiety, and related factors with the comfort of caregivers of patients with brain tumor in the preoperative phase

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**Background:** Brain tumors is a disease that seriously threatens life. It directly impacts patients with brain tumors and caregivers. Previous literature examined the relationship between stress and anxiety in caregivers of patients with a brain tumor. However, to date, the relationships of stress, anxiety, and related factors with comfort for caregivers of patients with brain tumors in the preoperative phase, using a framework derived from the Commonsense Model of Illness Representation, had not yet been examined.

**Objective:** This study aimed to examine the relationships of stress, anxiety, and related factors with comfort of caregivers for patients with a brain tumor in the preoperative phase.

**Methods:** Ninety-four caregivers of patients with a brain tumor were recruited from an in-patient department of a tertiary care hospital, Bangkok. Data were collected, using questionnaires composed of demographic information, information received, comfort after receiving information, stress, and State Trait Anxiety Inventory Form Y-1. Descriptive statistics, Pearson's correlation, and Spearman's Rank correlation were used to analyze the data.

**Results:** The results revealed that most subjects had moderate anxiety and tended to be more stressful. The subjects moderately received information regarding brain tumors and reported more comfort. There was a negative relationship between anxiety and comfort after receiving information ( $r = -0.36$ ;  $P < 0.001$ ). There were no relationships of age, educational level, stress, and information-receiving with comfort. There was no relationship between information receiving and comfort.

**Conclusions:** The findings of this current study could be directly applied to help screen caregivers' understanding and to receive tailored information which is helpful to decrease anxiety and stress for caregivers in the future.

**Keywords:** Stress, anxiety, information-receiving, comfort, caregivers, brain tumors, preoperative phase.

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Brain tumors is one of the serious neurological problems in both Western and Eastern countries including Thailand.<sup>(1)</sup> The incidence rate of newly diagnosis cases of brain tumors in the Western and Eastern countries including Thailand varied.<sup>(1)</sup> However, all incidence rates in both Western and Eastern countries including Thailand tended to increase during 10 to 25 years.<sup>(2)</sup> Brain tumors directly impact the brain, cognitive, and emotional functions.<sup>(3,4)</sup> The physical symptoms occur based on the brain tumor's location.<sup>(5)</sup> Patients might also

be stressful from a loss of physical function, leading to deteriorate a job performance and to be anxious of their treatment.<sup>(6)</sup> Most patients with brain tumors are treated with brain surgery because the surgery of tumor removal has less risks of neurological damage when compared with other treatments (radiation and chemotherapy) and helps relieve worse symptoms.<sup>(7,8)</sup> However, it may cause severe complications including brain edema, increased intracranial pressure, intracranial hemorrhage, and a decrease of level of consciousness.<sup>(7)</sup> These complications are unstable, unpredictable, and uncontrollable, making caregivers feel stressful and anxious because they do not know what will happen with their love ones who are undergoing surgery<sup>(7,9-12)</sup> especially caregivers who do not know the progress of health information.<sup>(13)</sup>

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Age and educational levels are interesting in caregivers because they help integrate how caregivers should think and react to the patients with brain tumors with the comfort. Previous studies showed differences of age and educational levels helped caregivers adapt themselves for satisfaction (comfort).<sup>(14)</sup> In terms of anxiety, a previous study showed significant association between caregivers' anxiety and satisfaction (comfort).<sup>(15, 16)</sup> Additionally, previous studies showed various findings between caregivers' stress and satisfaction (comfort)<sup>(17, 18)</sup> which should be further investigated. From the literature review, stress and anxiety should be further explored because it is difficult to separate these two factors.

Information received has been used for decision making, caring patients, reducing uncertain situations, and increasing caregiver competence.<sup>(19 - 21)</sup> Comfort is important for caregivers of patients with brain tumors because it helps them feel relax and know how to prepare themselves to deal with the circumstance with patients' medical health condition and to be able to cooperate with health care providers in order to be ready to face and manage patients' health situation.<sup>(22 - 24)</sup>

As it is known that caregivers need to adapt themselves and receive health information when they have their loved ones ill. Caregivers' self-regulation of receiving information of brain tumors surgery can be explained by the Common Sense Model of Illness Representation (CSM). The CSM model is has been used for studies in acute and chronic illness patients such as dementia, and Alzheimer's disease.<sup>(25, 26)</sup> The concept of the CSM emphasizes a person is a problem-solver when he/she is stimulated either physical or emotional threats and helps find solutions to reach better health outcomes. However, the CSM has never been used in caregivers of patients with brain tumors in the preoperative phase. This study examined how caregivers perceived emotional threats when patients underwent brain tumor(s) surgery. They had to find a solution to solve problems called "coping procedure" in the CSM and the derived variable of "coping procedure" was "information-receiving." If caregivers successfully solve the problems, this would lead to the health outcomes called "appraisal" in the CSM and the derived variable of the "appraisal" was "comfort".

While taking care of patients with brain tumors with better quality needs good caregivers for caring,

caregivers are important persons who should be attended. If caregivers of patients with brain tumors do not know the clinical situation and background of the patient, it can be more anxious and stressful. However, caregivers' stress and anxiety in caring patients with brain tumors still lacks of study.

## Materials and methods

The purpose of this research study was to describe anxiety, stress, information receiving, and comfort and to determine the relationships among related factors including age, educational level, caregivers' stress, caregivers' anxiety, information receiving, and comfort in caregivers taking care of patients with brain tumors in the pre-operative phase.

This study used the Cohen's statistic power analysis<sup>(27, 28)</sup> to estimate a sufficient number of the sample. According to Cohen's<sup>(29)</sup> recommendations, an appropriate and minimum sample size is 94 subjects.

This study was conducted at a tertiary university hospital of Thailand where there were various types of patients coming to visit the hospital. All subjects in this study were as follows: having 18 years or older, being the main person to care for patients with brain tumors in the operative phase, having abilities in understanding and communicating in Thai language, and willing to participate in this study.

Questionnaire was composed of information of caregivers' patients with brain tumors in the preoperative phase including gender, age, educational level, and caregivers-patient relationship (spouses, offspring, parents, siblings, and so on) and medical information of the patient with brain tumors in the preoperative phase.

Visual Analog Scale was measured. Subjects made a mark on a long straight line (1 to 10 cm). The long straight line was measured from the left to the mark that the subjects marked which was the score of the stress.

The state trait anxiety inventory (STAI) Form Y-1 in Thai language version developed by Rungruangsiripan (1999) and it was modified to fit in with Thais.<sup>(30)</sup> The State Trait Anxiety Inventory (STAI) Form Y-1 was used for a state anxiety measurement in caregivers. There were 20 questions in the STAI Form Y-1 for a stage anxiety measurement with a 4-point rating scale in each item. The raw score of the STAI Form Y-1 was separately rated for positive and negative items. Ten positive items were on a 4-point rating scale (1 = lowest;

4 = highest). Ten negative items were on a 4-point rating scale (4 = lowest; 1 = highest). The total scores were summed.<sup>(30)</sup> The scores ranged from 20 to 80. All scores of anxiety were divided into three levels including low (20 - 39 points), moderate (40 - 59 points), and high (60 - 80 points) levels of anxiety.

Items of the information-receiving questionnaire for caregivers of patients with brain tumors in Thai version was built up based on caregivers' inquiry and literature review. It was derived from the "coping procedure" in the Common Sense Model of Illness Representation.<sup>(31)</sup> Subjects were asked about the contents of information-receiving. They were composed of twelve item questions with two possible answers including enough and not enough in each question. The total scores of an information-receiving questionnaire were summed. The scores ranged from 0 to 12.

Items of the Comfort Questionnaire for Caregiver of Patient with Brain Tumor in Thai version was built up and derived from the "appraisal" in the Common Sense Model of Illness Representations.<sup>(31)</sup> Respondents were asked to indicate their comfort. The comfort questionnaire was composed of 12 items on a 4-point rating scale (1 = none; 4 = high). Subjects were asked to rate the comfort scale. Positive statements were scored as they were stated. A caregiver's answer of "none" was given score "1" and the caregiver's answer of "high" was given score "4". The scores of a comfort after receiving information are ranged from 12 to 48.

The study has been approved by the Institutional Review Board (IRB) of Faculty of Medicine Ramathibodi, Mahidol University (no. 12-61-19). All caregivers agreed to participate in the study. Each caregiver signed an informed consent form for the confidentiality of their responses and the right to participate in the study.

**Statistical analysis**

The Statistical Package for the Social Sciences (SPSS) version 18.0 was used for coding and analysis. Descriptive statistics were used to analyze the

frequency of distributions, mean, and standard deviation (SD) for age, educational level, stress, anxiety, information-seeking behavior, and comfort of receiving information. Pearson's correlation coefficient analysis was used to analyze the relationships of age, stress, anxiety, information-receiving, and comfort after receiving information. The relationships of educational level (ordinal scale) and comfort was analyzed using Spearman's Rank correlation coefficient. *P* < 0.05 was considered as significant difference.

**Results**

Caregivers' characteristics of patients with brain tumors in the preoperative phase, ninety-four caregivers (n = 94) of patients with a brain tumor in the preoperative phase were recruited to this study. Most subjects were female caregivers (n = 69; 73.4%). The mean age was 44.34 years (SD = 13.7). Almost half of the subjects were middle-aged adults (n = 46; 48.9%). Most caregiver-patient relationships were spouses (n = 27; 28.7%) and offsprings (n = 27; 28.7%) groups. More than one-tenth (n = 10; 10.6%) of the caregiver-patient relationship was parents. The majority had an educational level of bachelor degree (n = 36; 38.3%).

The results showed that most subjects had moderate anxiety with the mean score of the anxiety of 43.7 (SD = 9.5) and the actual scores of subjects ranged from 25 to 68. Caregivers' stress was measured using a visual analog scale. The mean score of the caregivers' stress was 54.6 (SD = 26.1) and the scores of caregivers' stress ranged from 0 to 100. (Table 1).

On the scale of the State Trait Anxiety Inventory Form Y-1 (STAI Form Y-1), more than half of caregivers (54.3%) reported they were rated for "somewhat" in feeling clam and more than two-fifths (48.9%) of them were rated for "moderately so" in feeling comfortable in positive items. In negative items, more than 50.0% of caregivers reported that they were rated "somewhat" in "I am tense," "I am strained," and "I feel indecisive".

**Table 1.** Description of study variables for caregivers of brain tumors patients in the preoperative phase (n = 94).

Variables	Range of the scale	Min-Max	Mean	SD
Anxiety	20 - 80	25 - 68	43.7	9.5
Stress	0 - 100	0 - 100	54.6	26.1
Information-receiving	0 - 12	0 - 12	6.1	3.0
Comfort	12 - 48	12 - 48	33.9	6.8

On the scale of receiving information, more than 75.0% of caregivers reported they received information of brain tumors in patients' admission" and almost 75.0% of caregivers reported they received information regarding the risks and complications of brain surgery. Almost 70.0% of caregivers reported that they received information of the impacts of unexpected brain surgery. Almost 70.0% of caregivers did not receive information about patients' referral after surgery and they did not know how to follow-up the surgical processes. Approximately 60.0% of the caregivers did not receive information regarding the canceling or postponing the surgical planning. More than 55.0% of the caregivers did not receive information on patient's medical conditions after the operation was done and they did not know the information about the length of stay at the operating room.

On the scale of comfort, more than 40.0% of the caregivers had high comfort when they received information about the length of stay in the hospital and how to follow-up the surgical process. More than 35.0% of the caregivers felt uncomfortable after receiving general information of brain tumors. More than 55.0% of caregivers felt rather comfortable after receiving information about risks and complications of brain surgery. Most subjects (41.5%) reported they felt comfortable when they knew the patients' length of stay in the hospital.

The results showed that there was a negative association between anxiety and comfort after receiving information ( $r = -0.36$ ;  $P < 0.001$ ). This means the more the anxiety, the lesser the comfort. However, there were no associations of age, information receiving, stress, and comfort after receiving information (Table 2).

In terms of an educational level considered the level of measurement as ordinal scale, Spearman's rank correlation coefficient was used. There was no relationship between the educational level and comfort (Table 2).

## Discussion

Most subjects were middle adults (36 - 55 years) which is consistent with a previous study<sup>(7)</sup> that reported that more than fifty percent of subjects were middle-age adults.<sup>(7)</sup> It is not surprising that Thai caregivers were middle adults because most people in this group were in the working age and had to pay responsibilities to the family.<sup>(32)</sup>

Most subjects in this current study were females and the finding are consistent with previous studies<sup>(33-35)</sup> among caregivers of patients with brain tumors. In this study, most subjects had educational level of Bachelor's degree and it is relevant with one previous study.<sup>(35)</sup> However, an Australian study examining an educational level in caregivers of patients with brain tumors reported that most subjects had secondary school.<sup>(33)</sup> It is not surprising that the educational level for Thai caregivers was higher than that in Australia because the Thai educational structure encourages Thai people to have the education at least the level of Bachelor's degree according to Thai national regulation of high school graduation.<sup>(36)</sup> In term of caregiver-patient relationships, most caregivers in this current study were spouses and off springs similar to the previous studies in the US and in Australia.<sup>(33)</sup> At present, the structure<sup>(34, 37)</sup> of Thai family tends to be a nuclear family rather than extended family.<sup>(38)</sup> Thai spouses have to pay more responsibilities in the family and they have to play an important role to the family.

From the findings, most subjects reported moderate anxiety. This could be explained that the surgery situation of patients with a brain tumor can trigger caregivers to be more anxious<sup>(39)</sup> which is the common sense. The surgical situation is a stimulus triggering caregivers' emotions, making them unhappy. When looking at the subscales of STAI Form Y-1, all positive items, such as feeling calm and comfortable were rated from "somewhat to moderately so." All negative items, such as "I am tense", "I am strained", and "I feel indecisive" were rated "somewhat". The

**Table 2.** Summary of the relationship between independent variables and comfort scale.

Variables	<i>r</i>	<i>P</i> -value
Age	$r_{xy} = -1.340$	0.200
Educational level	$r_s = 0.004$	0.970
Anxiety	$r_{xy} = -0.360^{**}$	0.000
Stress	$r_{xy} = -0.050$	0.660
Information-receiving	$r_{xy} = 0.160$	0.120

Note. \* mean  $P < 0.05$ , significant relationship

$r_{xy}$  = relationship examined by Pearson's Product Moment Correlation

$r_s$  = relationship examined b Spearman's rank order correlation

positive items could be interpreted that many caregivers of patients with a brain tumor in this study used to contact the physician for patients' consultation of illness for some time. This made them feel sooth. However, they still reported negative feeling. This is possible because the patient's surgery might not be easy to be predicted what would happen with the patient with brain tumors. More than half of the subjects reported they felt stressed. This finding of the current study is congruent with a previous finding which studied stress among caregivers of the patients with brain tumors in Thailand.<sup>(7)</sup> This is possible because they felt the severity of the disease might be harmful to the patient' health. If this is explained through the CSM, it is similar to "anxiety". That is, stress is another emotional threat impacting caregivers' emotions. The findings showed the evidence that most subjects received information regarding the brain tumors in patients, risks and complications, and the unexpected impact of brain tumors surgery during the period of admission. However, a portion of caregivers and patients with brain tumors did not know how to receive patients' medical conditions after the operation is done, to follow up the surgical process, and to cancel or to postpone the surgical planning. This is possible because some surgical situations could not be predicted, making health care providers not be able to inform caregivers. More than half of the subjects reported they felt comfort after receiving information on risks and complications of brain tumors surgery. Approximately two-fifths of subjects felt comfort regards patients' length of stay in the hospital. This means it would be better if the communication of the health care system is improved. This will help caregivers be able to have a practical plan for caring for patients with a brain tumor in the future. However, around one-third of them reported discomfort after receiving general information of a brain tumor. This makes nurses should be aware 211 of information sharing with caregivers. Tailoring or giving types of information about a brain tumor before sharing with caregivers is necessary for nurses. In the current study, there was no relationship between age and comfort in caregivers of patients with a brain tumor. This finding is not congruent with the previous studies.<sup>(40, 41)</sup> This could be due to the difference between sample characteristics and research designs. The current study had samples as caregivers of patients with brain tumors whereas Al-Khashan's study had caregivers who used support health care

services provided by a military hospital. In addition, Al-Khashan's study reported various illnesses including injury, respiratory problems, other chronic diseases, injury, and concomitant diseases whereas the current study only focused on caregivers of patients with brain tumors, making the findings different. Furthermore, the current study was a correlational study with a face-to-face structural interview for a data collection of caregivers in patients with brain tumors in the preoperative phase while the previous study<sup>(40)</sup> was a cross-sectional study with a six-month telephone follow-up of the interview for a data collection. In Poland, there was a positive association between age and satisfaction for caregivers<sup>(41)</sup> which does not support the current study. The current study had caregivers who worried whereas caregivers from another study had no stimulus from serious environments.<sup>(41)</sup> Consequently, the findings could be different. However, this current study supports other previous findings<sup>(42,43)</sup> reporting that there was no association between age and caregivers' satisfaction in groups of patients with dementia and those with terminally ill cancers. This is possible because sample characteristics among studies had threatened diseases, like a brain tumor. This made the findings similar.

In the current study, there was no relationship between educational level and comfort. The study does not support the relationship between anxiety and information-receiving in some previous studies.<sup>(14, 42, 43)</sup> This is likely due to the fact that, in the current study, the subjects who are worried about brain tumors surgery tending to be more threatened than subjects from the previous studies<sup>(14, 41 - 43)</sup> had no stimuli from serious situations because they were caregivers in the groups of patients with dementia and other chronic illnesses in the home health care services. Situations, making the findings different.

The finding of the current study revealed a negative significant relationship between anxiety and comfort among caregivers of patients with a brain tumors. This finding supports an earlier study<sup>(16)</sup> showing that caregivers who were parents of children with asthma had to face with uncontrolled asthma, making the findings look similar. However, this current study does not support some other previous findings<sup>(15)</sup> reporting that there was no association between anxiety and caregivers' satisfaction in caregivers of children with HIV. This is possible because caregivers of children with HIV faced with

multiple stressors including illnesses and more health details linked to caring children. This could make the findings different.

In the current study, there was no relationship between stress and comfort. This finding supports a previous study.<sup>(18)</sup> A possible explanation for this consistent finding might be similar sample characteristics of neurological diseases.<sup>(18)</sup> Stress occurs when a person has to face with danger in the form of physical threat which might be dead. In this current study, caregivers felt a person whom they loved might be dead from serious illness. No matter how much information caregivers receive, this does not help them improve their comfort. However, this current study does not support the relationship between stress and comfort in the previous study<sup>(18)</sup> examining stress and satisfaction in grandparents when caring grandchildren. It is possible that there were various types (spouses and off springs) of caregiver-patient relationships in the current study while caregivers in the previous study were grandparents taking care of their grandchildren (healthy children). This could make the findings different.

In current study, there was no relationship between information-receiving and comfort. This finding is relevant to a previous study<sup>(22)</sup> stating that persons with more informational sources had no association with caregivers' satisfaction. It is possible that most subjects were caregivers of patients with a new diagnosis of a brain tumor. They had no experiences how to deal with this situation of bad news, making caregivers' feeling not different. Additionally, high anxiety in caregivers can decrease ability to understand information.

However, the current study does not support some previous studies<sup>(23,24)</sup> regards the relationships between information-receiving and comfort. The current study does not support Dubenske LL, *et al.*<sup>(23)</sup> who found a positive relationship between caregivers' information competence and their satisfaction. It is possible that the finding in this current study was different from another previous study<sup>(23)</sup> because the previous study examined the relationship between information competence and satisfaction in caregivers of patients with various types of cancers at the multistage including the metastasis stage. This could make the findings differ from those in the current study. Caregivers had received medical information and experiences in dealing with patients' health condition along with illness duration. This helps

caregivers be prompted to deal with the serious situation and not to be more anxious in order to understand information.

## Conclusion

Most caregivers received information of brain tumors which is good. However, before sharing information of brain tumors, nurses should consider before providing appropriate and meaningful information to fit with each caregiver. Nurses should make meeting with caregivers that might help search what caregivers need to know about their patient treatments better.

Strengths of this study are as follows: 1) This is the first time to explore information-receiving, comfort, anxiety, stress, and their relationships among caregivers of patients with brain tumors in Thailand. The foundation of evidence thus is developed in order to apply to assist caregivers in the future; 2) Data collections were done in an only tertiary care hospital, this hospital had various types of patients, this helped generalize sample characteristics; 3) The questionnaire of information-receiving for caregivers of patients with brain tumors and the comfort for caregivers of patients with brain tumors were Thai languages, these two questionnaires were considered acceptable for content validity and internal consistency reliability. These will benefit for applying the questionnaires for caregivers receiving health care services from the hospital; and, 4) The STAI Form Y-1 has been adopted to use in this study and has been already used in many previous studies with acceptable psychometric properties. This might help the strength of the study.

This study limited the exploration of some interesting variables. For example, financial support additional to Thai universal basic coverage might be explored for future research since the medical expenses of treating patients with brain tumors are costly. Although some caregivers stated they were housewives, some caregiver's occupations might also be explored because some occupations might be more anxious and stressful because they might be able to better search for information on brain tumors and complications, leading them to overwhelmingly receive information of disease. Additionally, applying the CSM generally has been examined in patients with various types of illnesses. However, this model was applied to investigate in caregivers and it might limit the exploration of examining the physical threat.

The findings in this study are meant to directly apply to help screen whether caregivers understand and receive tailored information which will be helpful for them to help decrease anxiety in the future.

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### Conflict of interest

The authors, hereby, declare no conflict of interest.

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