

Factors Affecting the Psychological Well-Being of Terminal Cancer Patient Caregivers in Muang District Uttaradit Province

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Background: Caring for terminal cancer patients is a heavy burden and complex. Caregivers take the important roles in caring. If caregivers could not adapt to the changing roles, this could negatively affect their health and they could be unable to continue taking care of the patients.

Objective: To investigate the factors affecting the psychological well-being of terminal cancer patient caregivers.

Materials and Methods: A descriptive study of terminal cancer patient caregivers in Muang Uttaradit District, Uttaradit Province was performed in the present study. The caregivers were selected using a systematic random sampling technique. Data was collected between June and September 2021. The data was analyzed using descriptive statistics, and stepwise multiple regression analysis.

Results: Two hundred fifty participants were included in the present study. The results showed that the participants had an overall moderate level of psychological well-being. Support from public health personnel, spouse, neighbors, and community, underlying diseases of caregivers, and resilience were predictive of psychological well-being. Five variables could predict the psychological well-being of terminal cancer patient caregivers by 60.2%.

Conclusion: Terminal cancer patient caregivers need support and assistance for enhancing psychological well-being according to predictable variables, which are concrete forms of activity.

Keywords: Terminal cancer patient caregivers; Psychological well-being; Social support; Resilience

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Cancer is a major public health problem in all countries around the world. By 2040, there will be 29.3 million new cancer cases and the mortality rate will rise to 16.3 million. In 2017, cancer was the leading cause of death in Thailand. There were 78,540 deaths from cancer, representing a mortality rate of 120.5 per 100,000 population, and this tends to increase⁽¹⁾. Terminal cancer illness has metastasized to other organs. The severity of the disease results in the patient experiencing pain and discomfort. These cause the patients to suffer both physically

and mentally, resulting in a decrease in the ability to care for themselves and a need to depend more on other persons⁽²⁾. Terminal cancer patient caregivers are family members who voluntarily provide care to the patients^(3,4). Studies on the impacts of being a terminal cancer patient caregivers found that they had low to moderate psychological quality of life⁽⁵⁾. Psychological well-being is a positive mental trait, a life satisfaction ability to control their own good health, with less anxiety or depression^(6,7). This consists of six components, self-acceptance, a purpose in life, individuality, beauty in oneself, a good relationship with other people, and the ability to manage the environment and psychological well-being of the terminal cancer patient. It is considered a critical issue that expresses health conditions. Therefore, the caregivers that receive health promotion, have a good psychological well-being, will be able to positively affect care.

Terminal cancer patients depend on caregivers with good psychological well-being who tend to take care of themselves or help the family to manage their thoughts and negative feelings. This

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effectively promotes perfect health, both physically and mentally. It also helps being accepted by society including being able to adjust and live in society happily⁽⁷⁾. Caregivers with high psychological well-being tend to be self-accepting. Having a positive attitude towards oneself and having confidence can help control or manage life's matters and provide a clear purpose in life. It also improves having good relationships with others⁽⁸⁾.

Between 2019 and 2021, in Uttaradit province, new cancer cases were 945, 1,211, and 880 cases, respectively, of which the proportion of the patients with terminal cancer reached 44.9%⁽⁹⁾. Most cancer was in Muang Uttaradit District⁽¹⁰⁾. Therefore, caregivers were required in larger numbers and their burden for caring for cancer patients increased. Currently, there is no direct policy on hospice care groups. Research on the study of factors related to the psychological well-being of terminal cancer patient caregivers is scarce. It was found that the main focus was on the caretaker. It is unclear how society supports the psychological well-being of caregivers. Therefore, the problem is not comprehensive. Consequently, the present study was interested to study the factors influencing the psychological well-being of terminally cancer patient caregivers in Muang Uttaradit District, Uttaradit Province, to know the level of psychological well-being problems. Use it as information for planning and developing strategies and policies and applying them to develop caregivers' psychological well-being in other areas. The present study aimed to investigate the factors affecting the psychological well-being of terminal cancer patient caregivers.

Materials and Methods

Methods

In the present study, the researchers used Ryff & Keyes's psychological well-being concept⁽⁷⁾, in conjunction with a review of relevant literature to study psychological well-being and factors affecting it. It was found that there were three factors affecting the psychological well-being of terminal cancer patient caregivers. They are the 1) personal factors of the caregiver, the perceived burden of care, resilience, and optimism, 2) personal factors of the terminal cancer patient, and 3) social support.

The present study was a descriptive predictive correlational research of factors predicting the psychological well-being of the 250 terminal cancer patient caregivers in Muang Uttaradit District, Uttaradit Province. Data was collected between June

and September 2021.

Participants (sample size)

The present study population was the primary caregiver of terminally cancer patients, aged 20 years old and older, domiciled in Muang Uttaradit District, Uttaradit Province. The exclusion criteria were caregivers with serious, sudden illnesses unable to provide information, and caregivers not in the area while conducting the present research. The number of samples determined was 250 caregivers from the study population of 1,380 caregivers by selecting from the sample size calculation using the populating mean estimation formula⁽¹¹⁾.

Research instrument

The tools used were seven questionnaires, consisting of:

Part 1: The caregiver's personal data questionnaire included age, gender, education, marital status, occupation, income, financial status, health status, involvement with the patient, relationship level, length of patient care, and sufficient knowledge and skills in patient care.

Part 2: The Palliative Performance Scale (PPS)⁽¹²⁾ is a standard questionnaire used by healthcare professionals to assess their ability to take care of themselves in daily life in various aspects. Palliative care was categorized into eleven levels ranging from 100% down to 0% to separate patients into three subgroups as stable for patients above 70%, terminally ill for patients between 0% and 30%, and in between these two groups for patients between 40% and 70%. Patients were assessed in five key areas as ability to move, disease activity and severity, self-care, food intake, and consciousness.

Part 3: The psychological well-being assessment form was based on Ryff & Keyes's⁽⁷⁾ concept translated into Thai and revised by Wichitsiri & Sawangsopakul⁽⁸⁾. It consisted of 18 questions. The mental health of the person looks at six elements, self-acceptance, having a good relationship with others, having the ability to control and manage their own environment, having a purpose in life, and personal prosperity.

Part 4: The Care Burden Questionnaire, based on Zarit Burden Interview (ZBI), Zarit et al. (1980), translated by Pankong⁽¹³⁾, is a 22 questions questionnaire designed to measure the caregiver burden. It is divided into no care burden, low, medium, and high care burden.

Part 5: The Social Support Assessment Form,

developed by House (1981)(14), consists of 15 questions assessing the caregiver's social support. It is divided into three parts as support from family, support from neighbors, and community, and support from health personnel. Each part has five questions, using a scale questionnaire or rating scale.

Part 6: The Optimism Questionnaire is based on the Yodrakang⁽¹⁵⁾ questionnaire, which is developed from the Life Orientation Test (LOT) questionnaire of Scheier, Carver, and Bridges (1994), asking about the expectations of the events that a person expects to happen, being positive or negative. It consists of five questions, three of which were positive (items 1, 3, and 5) and two were negatives (items 2 and 4). The answer style was multiple-choice based on the five estimations. A high score indicates high optimism, and a low score indicates less optimism.

Part 7: Resilience assessment form, created by Nintachun et al.⁽¹⁶⁾, developed from the Edith Henderson Grotberg's resilience concept, was divided into three components with 1) I am external support, 2) I have inner strengths, and 3) I am skilled in interpersonal relationship and have problem-solving skills. Twenty-eight questions evaluated the resilience using a scale questionnaire or rating scale. Answers were on a scale of 5, with 1 for strongly disagree, 2 for disagree, 3 for neutral, 4 for agree, and 5 for strongly agree. The total score in resilience was between 28 and 140 points. A high score indicates high resilience or high life strength.

Data collection

The Human Research Ethics Committee of Naresuan University approved the research, with IRB number P3-0095/2563. For the protection of the sample group, the researchers collected the data following the objectives and protecting the name of the participant. The data was kept confidential and would not be disclosed. The study did not have any impact on the participant. Questionnaires and data were stored only by the researchers and destroyed within one year after the research was completed.

Data analysis

The data was analyzed using a computer program with a statistical significance of 0.05. Personal data were analyzed by descriptive statistics using mean and standard deviation. The analysis of the factors predicting the psychological well-being of terminal cancer patient caregivers was done with stepwise multiple regression analysis.

Results

The characteristics of the terminal cancer patient caregivers found that the majority of caregivers were female at 69.6%, aged between 40 and 59 years in 58.8% and with a mean age of 45.8 years (SD 11.95). Most of them had spouse status at 59.6% and graduated with a diploma for 31.6%. Twenty-four percent of the caregivers worked in agriculture and 38.8% had a monthly income of more than 10,000 Baht, enough to spend but with no saving in 39.2%. Most of them had no underlying disease at 65.2% and 41.6% of them were children of the patient. Their relationship with the patient was very good in 55.2% of the caregivers. Most of the caregivers had a length of care of less than one year in 70.8% and 83.6% of the caregivers had not enough sufficient knowledge and skills in patient care, as shown in Table 1.

The characteristics of terminal cancer patients found that 65.6% of them were female with 50% aged over 60 years with an average age of 59.3 years (SD 11.07). Thirty percent had breast cancer and the PPS was between 40% and 70%, with an average of 60.8%, as shown in Table 2.

The psychological well-being of terminal cancer patient caregivers had moderate overall psychological well-being, with a mean of 53.16 (SD 5.03). Self-acceptance, autonomy, and purpose in life were at a moderate level. The aspect of having a positive relationship with others, environmental mastery, and personal growth were at a high level as in Table 3.

Factors influencing the psychological well-being of terminal cancer patient caregivers from the data analyses by stepwise multiple regression analysis, were the support from health personnel, spouse, support from neighbors and community, underlying disease of the caregiver, and resilience. In combination, all these factors could predict the psychological well-being of the caregivers by 60.2%. The most was support from health personnel, followed by a spouse, support from neighbors and community, underlying disease, and resilience as shown in Table 4.

From the analysis results, an equation describing the psychological well-being of terminal cancer patient caregivers could be written in the raw scores as follows:

Psychological well-being of terminal cancer patient caregivers = 30.809 + 0.450 (support from health personnel) – 0.869 (spouse) + 0.189 (support from neighbors and community) – 0.556 (underlying disease of caregiver) + 0.094 (resilience).

Table 1. Characteristics of the terminal cancer patient caregivers (n=250)

Characteristics	n	%	Characteristics	n	%
Sex			Income (Baht)		
Male	76	30.4	Minimum 0, maximum 50,000, mean 11,869, SD 9,857		
Female	174	69.6	Financial status		
Age (years)			Not enough	92	36.8
20 to 39	73	29.2	Enough not to keep	98	39.2
40 to 59	147	58.8	Enough to save	60	24.0
>60	30	12.0	Health status		
Minimum 22, maximum 75, mean 45.80, SD 11.95			No underlying	163	65.2
Marital status			Diabetes mellitus	33	13.2
Single	70	28.0	Hypertension	37	14.8
Spouse	149	59.6	Heart and blood vessels	8	3.2
Widowed	10	4.0	Dyslipidemia	5	2.0
Divorce	10	4.0	ESRD	2	0.8
Separated	11	4.4	Involvement with the patient		
Education			Child	104	41.6
Not studying	30	12.0	Spouse	76	30.0
Elementary school	74	29.6	Father/mother	10	4.0
Secondary/vocational certificate	42	16.8	Friend	28	11.2
Diploma/high vocational certificate	79	31.6	Relative	28	11.2
Bachelor's degree	20	8.0	Other	4	1.6
Master's degree	5	2.0	Relationship level		
Occupation			Fair	6	2.4
Agriculture	60	24.0	Moderate	14	5.6
Work for hire	40	16.0	Good	92	36.8
Trade	35	14.0	Very good	138	55.2
Company employee	54	21.6	Length of patient care (years)		
Government service/state enterprise	26	10.4	<1	177	70.8
Other	35	14.0	1 to 3	42	16.8
Income (Baht)			4 to 6	21	8.4
<5,000	74	29.6	>6	10	4.0
5,000 to 7,500	17	6.8	Sufficiency of knowledge and skills in patient care		
7,501 to 10,000	62	24.8	Not enough	209	83.6
>10,000	97	38.8	Enough	41	16.4

SD=standard deviation; ESRD=end stage renal disease

Discussion

From the results of the present study, it was found that factors influencing the psychological well-being of terminal cancer patient caregivers consisted of five factors in descending order, support from health personnel, spouse, support from neighbors and community, underlying disease of caregivers, and resilience. These variables were able to predict the psychological well-being of terminal cancer patient caregivers by 60.2% with a statistical significance at the 0.05 level.

Support from health personnel positively influences the psychological well-being of terminal cancer patient caregivers. As a result, influencing

the psychological well-being of terminal cancer patient caregivers increases. This is because medical personnel, such as doctors, nurses, public health workers, and other personnel support terminal cancer patient caregivers with information, support, suggestion, warning, counseling, and providing various forms of information. Other items such as instrumental support, such as medical tools used in patient care and helping caregivers in times of need⁽¹⁷⁾ are important. This is because social support is a fundamental factor affecting the ability to care for patients. These items give the caregivers positive mental health, reduce stress and anxiety, and create a feeling of self-acceptance and confidence in their

Table 2. Characteristics of terminal cancer patients (n=250)

Characteristics	n	%
Sex		
Male	86	34.4
Female	164	65.6
Age (years)		
20 to 39	13	5.2
40 to 59	112	44.8
>60	125	50.0
Minimum 37, maximum 84, mean 59.32, SD 11.07		
Cancer type		
Stomach	13	5.2
Lung	42	16.8
Liver and bile duct	16	6.4
Breast	75	30.0
Colorectal	50	20.0
Cervical	5	2.0
Leukemia	13	5.2
Esophagus	30	12.0
Others	6	2.4
Palliative Performance Scale (PPS)		
<40%	98	39.2
40% to 70%	152	60.8

SD=standard deviation

Table 3. The mean, standard deviation, and the lowest-highest score of the psychological well-being of terminal cancer patient caregiver

Variables	Mean	SD	Min	Max	Level
Self-acceptance	8.62	1.64	5	12	Moderate
Positive relations with others	9.06	1.34	5	12	High
Autonomy	8.40	0.94	6	10	Moderate
Environmental mastery	9.02	1.29	7	12	High
Purpose in life	8.44	1.61	4	11	Moderate
Personal growth	9.62	1.72	3	12	High
Psychological well-being (overall)	53.16	5.03	36	63	Moderate

SD=standard deviation

Table 4. The multiple regression analysis (stepwise) between prediction variables and the psychological well-being of terminal cancer patient caregivers (n=250)

Prediction variables	R square	R square change	Std. beta	b	SEb	t	p-value
Support from health personnel	0.255	0.252	0.313	0.450	0.076	5.900	<0.001
Spouse	0.520	0.062	-0.261	-0.869	0.164	-5.309	<0.001
Support from neighbors and community	0.590	0.017	0.144	0.189	0.063	3.014	0.003
Underlying disease	0.602	0.012	-0.144	-0.556	0.205	-2.438	0.007
Resilience	0.573	0.029	0.071	0.094	0.021	3.584	<0.001

Constant(a)=30.809, R square=0.602, Adjusted R square=0.587, F=40.386, p<0.001

ability to face problems⁽¹⁴⁾. This is consistent with the results of a study on the need for family support in caring for terminally ill cancer patients, which found that obtaining adequate information would enable caregivers to make decisions on patient care as well as plan/prepare the patient to leave peacefully. It is also for the mental preparation for family members before the patient's final day⁽¹⁸⁾.

Spouse status negatively affects caregivers' psychological well-being, explaining that caregivers involve spouses of terminal cancer patients. This is a person who has a close relationship with the patient. Therefore, the caregiver is faced with the near loss of a loved one that will occur. This may result in the main cause of mental health problems, including stress, anxiety, and depression⁽¹⁹⁾. The caregiver will also lack goals in life when the patient is not himself and in long-term care. As a result, caregivers have reduced psychological well-being, which will affect the spouse's relationship with the patient. Thus, this is a factor that affects the psychological well-being of caregivers of terminal cancer patients⁽²⁰⁾.

Support from neighbors and community positively affected the psychological well-being of terminal cancer patient caregivers. It was explained that increased support from neighbors and communities resulted in better mental health. People with close relationships assist in personal hygiene care for the patients and help with housework, giving caregivers time off from caring for the patients. Furthermore, the visits from encouraging people in the community provides psychological support that can help reduce stress in caregivers⁽²¹⁻²³⁾. This is consistent with a study by Cassidy & McLaughlin⁽²⁴⁾, where neighbor and community support positively affect psychological well-being.

The underlying disease of caregivers negatively affects the psychological well-being of terminal cancer patient caregivers, explaining that caregivers without underlying diseases are more readily available to care

for terminal cancer patients than those who have underlying diseases such as diabetes, hypertension, dyslipidemia, or osteoporosis. If the caregivers do not take care of themselves or receive continuous treatment, because of helping the patient in doing daily activities and performing various activities without a break, it might increase the severity of the disease of the caregivers, deteriorating their health, and causes fatigue and discouragement^(25,26). This affects mental health, and causes symptoms of stress, anxiety, loneliness, fear, guilt, and lack of self-acceptance⁽¹⁹⁾. This is consistent with the study by Kaewpipob et al.⁽²⁷⁾, which found that caregivers with underlying diseases were 3.71 times more likely to develop mental health problems than caregivers without underlying diseases. The underlying disease of caregivers is another factor that directly affects psychological well-being.

Resilience positively affects the psychological well-being of terminal cancer patient caregivers. Resilience is described as the caregiver's ability to withstand difficult events and can recover quickly. Caregiver with high resilience will be able to deal with difficult situations in caring for the patient more effectively, resulting in high psychological well-being⁽²⁸⁾. This is consistent with the study of Detchaiyot et al. that found the life stamina was a positive factor in mental health⁽²⁹⁾.

Conclusion

The present study described factors that affect the psychological well-being of terminal cancer patient caregivers. The findings showed that five variables contributed to the psychological well-being of the terminal cancer patient caregivers, which are support from public health personnel, spouse, support from neighbors and community, underlying disease, and resilience. Therefore, the model of enhancing psychological well-being promotion should be studied in the next research on terminal cancer patient caregivers. This will lead to a good effect on the psychological well-being of the terminal cancer patient caregivers.

What is already known on this topic?

Caring for a terminal cancer patient is a heavy burden and complicated. If caregivers are unable to adapt to changing roles, their mental health will be affected in many ways.

What this study adds?

The results showed that participants had an

overall moderate level of psychological well-being. Support from public health personnel, spouse, support from neighbors and community, underlying disease of caregivers, and resilience were predictive of psychological well-being.

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Conflicts of interest

The authors declare no conflict of interest.

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