

## Effects of Empowerment Program on Empowering and Caring Behaviors among Caregivers for Patients with Malnutrition of Head and Neck Cancer

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**Received:** 27 November 2020; **Accepted:** 15 December 2020

**Citation:** Chaikham R, Raksanaves L, Pichaya N, et al. Effects of Empowerment Program on Empowering and Caring Behaviors among Caregivers for Patients with Malnutrition of Head and Neck Cancer. *Nur Primary Care*. 2020; 4(7): 1-6.

### ABSTRACT

**Background:** This quasi-experimental research was to investigate the effects of empowerment programs on caregivers in caring for head and neck cancer patients with malnutrition.

**Methods:** A random sampling was used to recruit a sample of 30 caregivers, divided into 15 caregivers in the experimental group and 15 in the control group. Data were collected between April 2019 to August 2019. The experimental group received individual empowerment programs and the control group received regular training, over a total of 8 weeks. The structured interview used for data collection included perceived empowered and caring behaviors in the period pre-experiment, immediately after the experiment, and one month after. Data were analyzed using repeated measures ANOVA.

**Results:** 1) The caregivers in the experimental group had a mean score of the perceived empowered and caring behaviors in the period immediately after the experiment and one month after higher than in the period pre-experiment at the 0.05 level of significance. 2) The caregivers in the experimental group had a mean score of the perceived empowered and caring behaviors in the period immediately after the experiment and one month after, higher than the control group at the 0.05 level of significance.

**Conclusion:** The findings are beneficial for nurses and related parties using the empowerment program as the key tool to increase feelings of empowerment in caregivers and improve their caring behavior with respect to their care of malnourished head and neck cancer patients, and achieving a good quality of life for them.

### Keywords

Empowerment, Malnutrition, Caregiver, Head and Neck cancer.

### Introduction

Cancer is the number one cause of death in Thailand and is likely to increase [1]. Head and neck cancer in Chonburi Cancer Hospital is the topmost cancer, accounting for an average of 280 people per year or 13.10% of all new patients, according to statistics from 2012 to 2016 [2]. There are many methods of treatment, such as surgery, chemotherapy, and radiotherapy, or a combination of methods [3]. The treatment causes side effects, including inflammation of the oral mucosa. Taste changes, reduced saliva

causing dryness, nausea and vomiting, which affects malnutrition [4] chemotherapy is associated with a mucositis risk of 60-100%, while the combination of chemotherapy and radiotherapy implies a risk of almost 100% [5] which caused discomfort, pain, and suffering. If severe, symptoms will affect the ability to eat food and drink water.

The size of the tumor pressing against the gastrointestinal tract can cause pain and act as a barrier to eating food and taking water through the mouth as well. This can affect the quality of life of patients and increase the risk of malnutrition which in turn increases the incidence of postoperative complications such as slow healing,

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low immunity and infections, also increasing the rate of illness and death [6]. Other complications include a longer hospital stay and increased treatment costs [7]. The most common problem in head and neck cancer patients is malnutrition. Caregivers have an important role in helping to support and encourage patients to understand the disease and side effects from treatment, including encouraging patients to practice nutritional behavior appropriately and continuously to prevent complications arising from treatment.

Head and neck cancer patients are considered chronic patients requiring long-term care and ongoing support. If they having malnutrition as well, they naturally receive more complicated care from the caregiver. However, if the caregivers still lack knowledge about the disease, and lack experience, confidence, and the ability to take care of and correct nutrition problems, they will feel frustrated with the thought that care is a burden. These things can cause the caregivers to feel a loss of power (experience powerlessness) [8].

The majority of caregivers are relatives or family members. Long and continuous care can produce fatigue in relatives or family members, as well as feeling a burden, annoyance, difficulty, stress, anxiety, depression, despair, resulting in weak mental health and suffering, thereby undermining the physical and mental condition of the caregiver [9]. Promoting the caregiver's potential in caring for head and neck cancer patients is important, leading to a better quality of life for patients and caregivers. The empowerment of caregivers who care for head and neck cancer patients with malnutrition can be increased.

This research uses Gibson's empowerment process [10]. This is a strategy to develop caregivers to be more effective in caring for head and neck cancer patients with malnutrition. This research aimed to study the effects of empowerment programs to increase the potential of care for patients with malnutrition in head and neck cancer to improve quality of life.

## Materials and Methods

In a quasi-experimental research, two groups were repeated for three phases in pre-experiment, post-experiment and one-month follow-up of experimentation in the caregivers between the ages of 20–60 years who care for head and neck cancer patients with malnutrition ( $BMI < 18.5 \text{ Kg} / \text{M}^2$ ) at the outpatient department of Chonburi Cancer Hospital.

We calculated the sample group using the program GPower 3.1 to determine effect size as 1.025 [11]. Statistical significance was at the level of 0.05 and power analysis = 0.80. The sample group of 13 subjects but found that increasing the sample size to 15 subjects per group reduced the drop-out rate. [12]. The researcher recruited a total of 30 subjects.

## Measures

1. Personal data of participants, consisting of gender, age, income, education, occupation, relationship with patients, duration of care,

hours of care per day, Experience in maintaining, address and telephone number.

2. Personal data of patients, consisting of gender, age, disease stage, organ, weight (kg), height (centimeters), body mass index (BMI) ( $\text{Kg} / \text{M}^2$ ), type of treatment, illness duration, education level, occupation, marital status, family type, and symptoms.

3. The measure of power perception of caregivers contains 18 items, the answer is depicted as a 4 level estimation where 4 = High, 3 = Moderate, 2 = Low and 1 = Very Low. The total score ranges from 18 to 72 points. High scores mean a high level of power perception.

4. The measure of caring behaviors of caregivers contains 19 items, the answer is depicted as a 4 level estimation: 4 = High, 3 = Moderate, 2 = Low and 1 = Very Low. The total score ranges from 19 to 76 points. High scores mean a high level of caring behavior of caregivers.

5. The form for recording the weight of each of the patients.

6. Empowerment program on empowering and caring behaviors among caregivers for patients with malnutrition of head and neck cancer. The research was built on the concept of Gibson's empowerment consisting of four phases: 1) Discovering reality; 2) Critical reflection; 3) Taking charge; 4) Maintenance.

7. Care book for caregivers of head and neck cancer patients with malnutrition.

A content validity index (CVI) tool 3 and 4 by three experts was 0.93 and 0.94, respectively, and the Cronbach's alpha coefficient reliability was 0.89 and 0.90 respectively. Data were analyzed by using the SPSS program using descriptive statistics and Repeated Measures ANOVA.

## Compliance with Ethical standards

The study was approved by the IRB Chonburi Cancer Hospital. Project code 10/2561, and informed consent was obtained from the study participants. There was no conflict of interest.

## Procedure and Data Collection

A sample group of 30 participants were randomly assigned to an experimental group and a control group, with 15 in each. The experimental group received an empowerment program on empowering and caring behaviors among caregivers for patients with malnutrition associated with head and neck cancer. Data collection occurred three times, consisting of pre-experiment, post-experiment, and one-month follow-up of experimentation. The control group received regular care. We explained the purpose of the research and had the investigators sign a consent form. If there was any adverse reaction, the study participants could stop immediately.

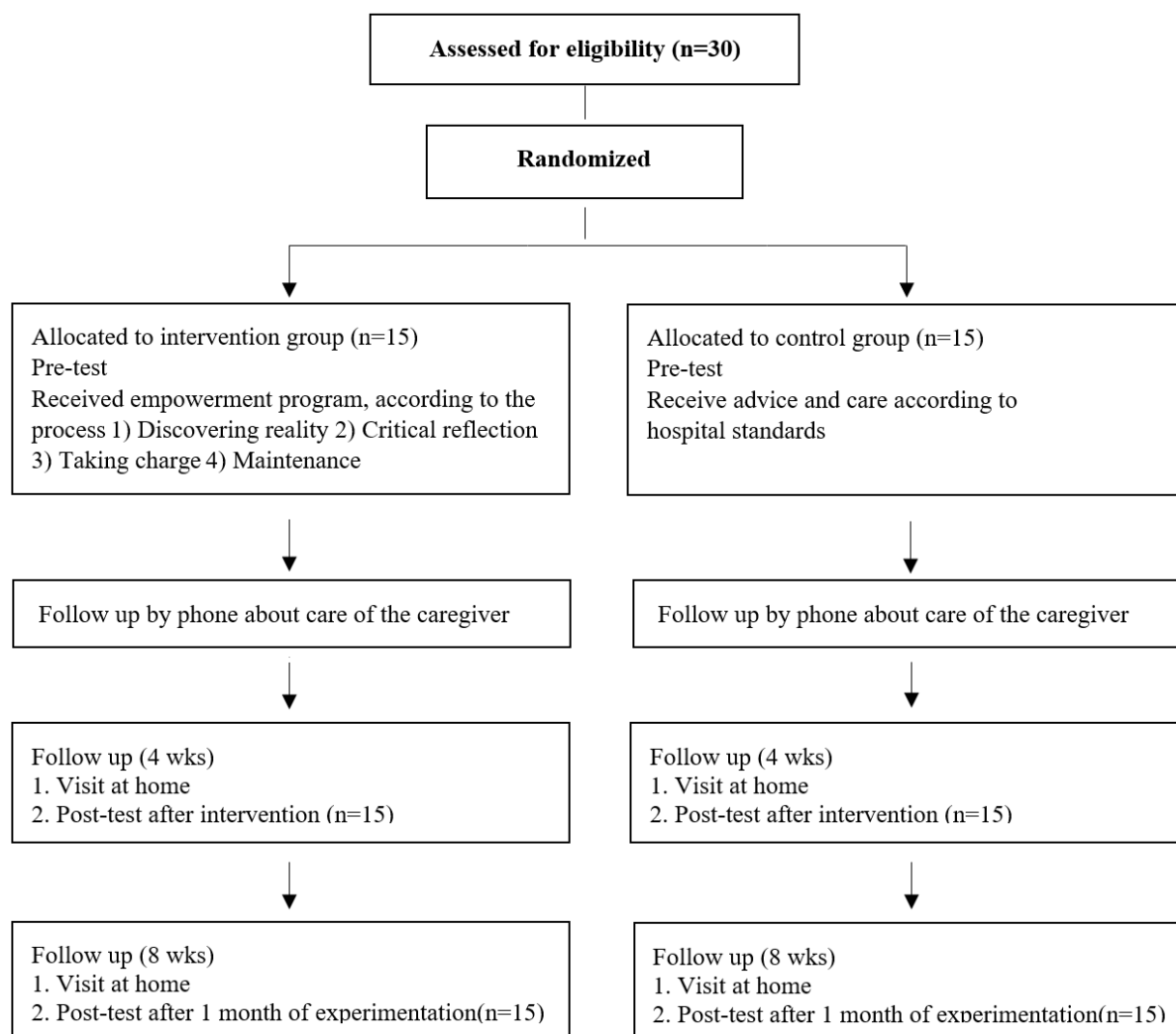


Figure 1 Flow diagram.

**Table 1:** Empowerment program on empowering and caring behaviors among caregivers for patients with malnutrition of head and neck cancer.

Session	Objective	Activity
Week 1 (2 hrs)	1. Build relationships to trust. 2. Caregivers have knowledge about head and neck cancer.	1. Create relationships with caregivers. 2. Explain the process of activities and handing outpatient care guidelines to caregivers. 3. Pre-test. 4. The researcher provided knowledge about head and neck cancer. 5. Exchange knowledge, and experience with caregivers. 6. Review patient care based on experience. 7. Analyze, summarize and prioritize problems. 8. Choose to solve problems together for implementation.
Week 2 (2 hrs)	For caregivers decide on the right practice for yourself, be able to solve problems systematically and create a commitment to practice.	1. Reviewing the problems and barrier in the care of patients with head and neck cancer in the past. 2. Find the best and suitable solution. 3. Compliment, support, encourage and instill confidence in caregivers to maintain quality practices.
Week 3 (30 min)	To follow up to give feedback and motivate caregivers to maintain quality and continuous care for patients.	1. Follow up by phone about care of the caregiver.
Week 4 (30 min)	To follow up on the home visits, make inquiries, and provide suggestions for solutions to problems and motivate caregivers to maintain consistent and quality patient care practices.	1. Visit at home. 2. Post-test after intervention.
Week 8 (30 min)	Maintenance	1. Visit at home. 2. Post-test after 1 month of experimentation.

## Results

It was found that, of the caregivers in the experimental group of 15, most: were female (80%); between 25 and 35 years old (33.3%) ( $M = 45.6, SD 13.40$ ); had income that was adequate (93.3%); had a secondary education (46.7%) and a primary education (40%); were employed (46.7%), and in agriculture (26.7%). The caregiver was either the husband or wife (40.6%), followed by grandchildren (30%). The duration of care was 1 to 3 month (80%), and the care given per day was from 1 to 8 hours (40%) and 9 to 16 hours (40%). No one had experience in care (100%).

**Table 2:** Personal data of caregivers.

Characteristics		Treatment (15)		Control (15)	
		n	%	N	%
Sex	Female	12	80.0	11	73.3
	Male	3	20.0	4	26.7
	Total	15	100	15	100
Age	25 – 35 years	5	33.3	4	26.7
	36 – 45 years	2	13.3	3	20.0
	46 – 55 years	4	26.7	3	20.0
	56 – 65 years	4	26.7	5	33.3
	Total	15	100	15	100
	Mean	$(M 45.6, SD 13.40)$		$(M 46.9, SD 13.06)$	
Income	Adequate	14	93.3	15	100.0
	Inadequate	1	6.7	0	0
	Total	15	100.0	15	100.0
Education	Primary	6	40.0	6	40.0
	Secondary	7	46.7	7	46.7
	Bachelor/ Higher	2	13.3	2	13.3
	Total	15	100.0	15	100.0
Occupation	Employed	7	46.7	7	46.7
	Agriculture	4	26.7	5	33.3
	Trader	3	20.0	3	20.0
	Not working	1	6.7	0	0
Total	15	100.0	15	100.0	
Relationship	Husband/Wife	6	40.0	5	33.3
	Descendant	4	26.6	6	40.0
	Father/Mother	1	6.7	0	0
	Brethren	1	6.7	4	26.7
	Grandchild	3	20.0	0	0
	Total	15	100.0	15	100.0
Duration of care	1 – 3 Month	12	80.0	10	66.7
	4 – 6 Month	3	20.0	4	26.7
	10 – 12 Month	0	0	1	6.6
	Total	15	100.0	15	100.0
Care per day	1 – 8 hours	6	40.0	7	46.7
	9 – 16 hours	6	40.0	8	53.3
	17 – 24 hours	3	20.0	0	0
	Total	15	100.0	15	100.0
Care experience	Never	15	100.0	15	100.0

The caregivers in the control group consisted of 15, mostly female (73.3%), who were between 56 and 65 years old (33.3%) (Mean 46.9,  $SD 13.06$ ). They had an income that was adequate (100%), a secondary education (46.7%) and a primary education (40%) and were employed (46.7%), mainly in agriculture (33.3%). The caregiver was the descendant (40.0%) or husband /wife (33.3%). The duration of care was 1 to 3 month (66.7%) or 4 to 6 month

(26.7%), and the amount of care per day from 9 to 16 hours (53.3%) or from 1 to 8 hours (46.7%). Again, no one had prior experience in care (100%).

**Table 3:** Mean scores, empowering and caring behaviors in the experimental group and the control group.

Variables		Experimental (n=15)		Control (n=15)		t-value	df	p-value
		M	SD	M	SD			
Empowering	T1	46.93	6.87	48.53	7.18	-0.62	28	0.538
	T2	58.40	4.17	52.93	6.51	2.736	28	0.011
	T3	64.60	3.60	54.86	7.38	4.588	28	0.000
Caring behaviors	T1	53.20	8.06	52.60	6.99	0.218	28	0.829
	T2	60.33	6.00	56.00	5.25	2.103	28	0.045
	T3	67.26	3.89	58.80	4.84	5.273	28	0.000

Note: T1 = week 0, pre-experiment; T2 = week 4, post-experiment; T3 = week 8, follow-up 1 month.

From Table 3, the mean score of empowering of caregivers pre-experiment, post-experiment and at one month follow-up was 46.93 ( $SD = 6.87$ ), 58.40 ( $SD = 4.17$ ) and 64.60 ( $SD = 3.60$ ) respectively and the control group had mean scores of 48.53 ( $SD = 7.18$ ), 52.93 ( $SD = 6.51$ ) and 54.86 ( $SD = 7.38$ ) respectively.

The mean score of caring behavior of caregivers pre-experiment, post-experiment and at one month follow-up in the experimental group was 53.20 ( $SD = 8.06$ ), 60.33 ( $SD = 6.00$ ) and 67.26 ( $SD = 3.89$ ) respectively and the control group had mean scores of 52.60 ( $SD = 6.99$ ), 56.00 ( $SD = 5.25$ ) and 58.80 ( $SD = 4.84$ ) respectively.

From the experiment, it was found that the mean scores for empowering and caring behaviors of the caregivers pre-experiment in both the experimental group and the control group were not different.

**Table 4:** Results of variance analysis of the mean score empowering of caregivers between the experimental method and the duration of the experiment.

Source of variation	SS	df	MS	F	p
Between subject					
Groups	462.40	1	462.40	5.62	0.025
Error	2305.42	28	82.34		
Within-subject					
Time	2234.75	2	1117.38	72.66	0.000
Time * Group	491.46	2	245.73	15.98	0.000
Error Time	861.11	56	15.38		
* $P < 0.05$					

From Table 4, it can be seen that there was a significant interaction between the experimental methods and experimental periods at the level of 0.05. The mean score of empowering of caregivers pre-experiment, post-experiment and at one month follow-up was significantly different at the level of 0.05 and the mean scores of

empowering of the caregivers in the experimental group and the control group showed differences that were statistically significant at the level of 0.05.

**Table 5:** Results of variance analysis of the mean score for caring behaviors of caregivers between the experimental method and the duration of the experiment.

Source of variation	SS	df	MS	F	p
Between subject					
Groups	448.90	1	448.90	5.45	0.027
Error	2304.67	28	82.31		
Within-subject					
Time	1541.07	2	770.53	59.60	0.000
Time * Group	232.27	2	116.13	8.98	0.000
Error Time	724.00	56	12.92		
* P < 0.05					

From Table 5, it is found that there is an interaction between the experimental method and the experimental period with statistical significance at the level of 0.05. The mean score of caring behavior of caregivers pre-experiment, post-experiment, and at one month follow-up was significantly different at the level of 0.05 and the mean scores of empowering of the caregivers in the experimental group and the control group showed differences that were statistically significant at the level of 0.05.

From Table 6, comparing the duration of the experiment within the experimental group, it was found that the mean scores of empowering in each stage were significantly different (p-value < 0.001) and the mean score of caring behavior of the caregivers in each phase was a statistically significant difference (p-value < 0.001).

**Table 6:** Pairwise comparisons of mean differences for the empowering and caring behavior of caregivers at each time of the experiment by using bonferroni method.

**Table 7:** Comparison of body weight and body mass index of patients in the experimental group and the control group at each stage of the experiment.

Patients in the experimental group								Patients in the control group							
No.	Pre-experiment			Post-experiment		Follow-up at 1 month		No.	Pre-experiment			Post-experiment		Follow-up at 1 month	
	BW.	High	BMI	BW.	BMI	BW.	BMI		BW.	High	BMI	BW.	BMI	BW.	BMI
1	43.8	165	16.09	44.2	16.23	45.5	16.71	1	45.5	170	15.74	46	15.92	46.1	15.95
2	47.5	175	15.51	47.7	15.57	48	15.67	2	33	150	14.67	33	14.67	34	15.11
3	47	160	18.36	49	19.14	50.2	19.60	3	39	165	14.33	39.5	14.51	38	13.96
4	51	170	17.65	50.5	17.47	52	17.99	4	50.2	165	18.44	50	18.37	52	19.10
5	44.4	170	15.36	47	16.26	46.1	15.95	5	44.9	164	16.69	52	19.33	50	18.59
6	36	157	14.61	39	15.82	37.3	15.13	6	36	162	13.73	37	14.10	36.8	14.02
7	37	150	16.44	38	16.88	39	17.33	7	43.2	162	16.46	43	16.38	44	16.77
8	47	160	18.36	49.4	19.29	51	19.92	8	44.7	172	15.11	43.9	14.84	44.5	15.04
9	46.6	164	17.33	47.2	17.54	48.3	17.95	9	50	165	18.36	52	19.10	51	18.73
10	40.8	160	15.94	39.7	15.50	43	16.79	10	48	165	17.63	47	17.26	49	18.00
11	48.6	168	17.29	49.5	17.53	52	18.42	11	48	167	17.21	47.1	16.89	48.2	17.28
12	41	162	15.62	42.1	16.04	43	16.38	12	45.1	161	17.40	43	16.59	44	16.97
13	42	165	15.43	45	16.52	48	17.63	13	37.7	171	12.89	39	13.34	38	13.00
14	46.3	166	16.82	45.2	16.40	46.7	16.94	14	40.6	158	16.26	42	16.82	42.5	17.02
15	55	175	17.96	57.1	18.64	59	19.26	15	50	165	18.36	51	18.73	50.5	18.55
		$\bar{x}$	16.58	$\bar{x}$	16.98	$\bar{x}$	17.44			$\bar{x}$	16.21	$\bar{x}$	16.45	$\bar{x}$	16.54

Note: BW = body weight (kg.); BMI = body mass index (kg/m<sup>2</sup>).

Time			Experimental group (n=15)			Control group (n=15)		
			MD	SD	P- value	MD	SD	P- value
Empowering								
T1	vs.	T2	-11.46**	1.06	0.000	-4.40*	1.31	0.014
T1	vs.	T3	-17.66**	1.98	0.000	-6.33*	1.89	0.015
T2	vs.	T3	-6.20**	1.13	0.000	-1.93	0.81	0.097
Caring behaviors								
T1	vs.	T2	-7.13**	1.33	0.000	-3.40*	0.75	0.001
T1	vs.	T3	-14.06**	1.80	0.000	-6.20*	1.36	0.001
T2	vs.	T3	-6.93**	1.49	0.000	-2.80*	0.82	0.013

Note: T1 = week 0, pre-experiment; T2 = week 4, post-experiment; T3 = week 8, follow-up 1 month. \* (P < .05), \*\* (P < .001)

## Discussion

The results found that the caregivers in the experimental group had a mean score of empowering and caring behavior post-experiment and at one month follow-up that was higher than pre-experiment with a statistical significance of 0.05.

The researcher conducted activities based on the empowerment program based on Gibson's concepts. These activities included: building relationships so that the caregivers can be trusted, feel relaxed and reveal real problems; teaching about the disease and taking care of patients with malnutrition; reviewing knowledge between the caregivers and researchers; reviewing the practice of caring for head and neck cancer patients to receive adequate food and energy by learning from experience; summarizing the importance of the problem and finding a suitable solution according to the patients and the caregivers. Researchers help and provide support in making the right discrimination decisions to caregivers and follow up the second time with the same procedure. Then they follow up on the phone and visit the home. Therefore, the level of the caregivers' perceived power and behavior was increased and that the persistence in the changes in the caregivers was apparent by week 4 and that it continued at follow-up [13-16].

The caregivers in the experimental group had mean scores of perception, power, and care behaviors, both immediately after the trial was completed and at one month post-trial, which were statistically significantly higher than that of the control group at 0.05. The building of empowerment in the caregivers towards their perception of power and behavior in caring for patients with malnutrition of head and neck cancer has been developed to make the main carers have knowledge, correct understanding and development of skills.

In addition, there is a close monitoring and evaluation of the care potential every week, as well as provision of recommendations for the caregivers to adjust their care behavior to suit both physically and psychosocially. As a result, the levels of perceived power and care behaviors were higher than those of the control group [17,18].

### Conclusions

- Implementing the empowerment program for caregivers to increase awareness of empowering and caring behavior for patients with malnutrition of head and neck cancer requires nurses or health personnel to have specific knowledge. The ability to organize group activities depends upon having good skills in carrying out such activities. The format can be adjusted as appropriate according to the potential and needs of the caregivers for effective results.
- Need to integrate the empowerment program for caregivers of head and neck cancer patients with malnutrition in hospital with home visit tracking to develop the capacity of caregivers to care appropriately for their patients at home as well.
- The research results provide information towards crafting guidelines for the caring of head and neck cancer patients with malnutrition by caregivers by using empowerment techniques.

### Limitations

It can be seen that patients with head and neck cancer during treatment have side effects that can affect body weight. However, when comparing the body weight of each group of patients, it was found that there is a distinct difference. But when comparing the differences in body mass index in each group of patients, they are quite similar in each phase. Therefore, the weight should be monitored for a longer period of time to assess the difference of the body mass index more clearly.

### Grant support

This research was supported by the Department of Medical Services Foundation, Thailand.

### Acknowledgements

Thank you, Assist. Dr. Somsamai Rattanaagreeethakul, Advisor and Dr. Akarathan Jitnuyanont, the director of Chonburi cancer hospital, for his support and encouragement of successful research.

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